

AN EXPLORATION OF THE EXPERIENCES OF PAID SOCIAL
CARE STAFF WHO HAVE SUPPORTED AND/OR CURRENTLY
SUPPORT PEOPLE WITH LEARNING DISABILITIES LIVING
WITH CANCER IN RESIDENTIAL SERVICES ACROSS WALES:
A GROUNDED THEORY STUDY.

TINA CRIMES

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**“When it comes to the pinch,
human beings are heroic.”**

George Orwell

(English Novelist and Essayist, 1903-1950)

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Glossary of terms

An alphabetical list of words and/or terms (a glossary) related to this study is given below. Meanings and explanations of the words are given on the right.

NO	TERM	DESCRIPTION
1	Deinstitutionalisation	The discharge of institutionalised people into the community
2	Paid social care worker	A worker providing social care support
3	Palliative care	Specialised care for people with serious illness
4	Post-operative	Care given after surgery
5	Primary healthcare	First contact essential health care usually via the person's general practitioner
6	Secondary healthcare	Healthcare provided by specialist or facility upon referral by a primary care physician
7	Residential services	A community home that provides assisted living facilities
8	Resilience	The capacity to recover quickly from difficulties
9	Service organisations	Third sector organisations providing social care support for tenants/ people with learning disabilities
10	Tenant	A person with learning disabilities who has a tenancy with a housing provider

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Abstract

Background: - People with learning disabilities are living longer. Increased longevity ensures the learning disability population is vulnerable to age related illnesses, such as cancer. Juxtaposed with the deinstitutionalisation movement of recent decades and the resulting growth and increasing demand for community based, supported living arrangements, many residential services are experiencing higher levels of ageing tenants who may be vulnerable to cancer. This is placing a responsibility on paid social care staff that may have little or no healthcare training, but are increasingly expected to support tenants who may have cancer. Little is known about how paid social care staff experience the development and ongoing challenges of their tenants' health conditions.

Aim: The aim of this research is to explore the experiences, challenges and support needs of paid social care staff supporting people with learning disabilities living with cancer in residential services across Wales.

Method: This study has adopted a qualitative paradigm and a symbolic interactionist perspective to explore participants' experiences. Data was collected from analysis of 14 semi-structured interviews. Theory was generated simultaneously using Charmaz's (2010) version of constructivist

grounded theory. Since existing evaluation criteria did not adequately address the study design the researcher has developed an original framework of evaluation criteria for this study.

Findings: Findings indicate four theoretical categories emerging from the data. These are: - role identity (how staff see their role), role ambiguity (how supporting a tenant with cancer changes their role), role emotions (how staff feel about these changes) and role resolution (how staff try to cope, resolve and prepare for these changes).

Supporting a tenant with an illness such as cancer requires significant adjustments to the social care role. These adjustments blur social care role boundaries. For example, social care staff are expected to undertake healthcare tasks, such as administering illness specific pain relief and/or providing post-operative care. These changes to the staff role identity produce role ambiguity. Role ambiguity creates a series of role emotions leading staff into a process of role resolution where they attempt to resolve role ambiguity and create positive role emotions. This cyclical process inadvertently helps staff to build resilience. Resilience results from basic human adaptation systems. Resilient individuals can adapt to adversity and offset negative experiences with positive ones.

Conclusion: Social care roles increasingly require a significant component of healthcare (a fact that is not widely recognised) and there is a need to

ensure staff have *prior* adequate resilience attained through appropriate training and support to equip them in the challenges they will be expected to meet ahead.

Introduction

Cancer is an inclusive disease and affects people with learning disabilities as well as the wider population. However, people with learning disabilities may require additional support and their experience may differ from other people. With increased numbers living in supported living settings, ensuring appropriate care when cancer occurs may challenge learning disability services. This thesis aims to explore the experiences, challenges and support needs of paid social care staff supporting people with learning disabilities living with cancer in residential services in Wales. This chapter consists of three sections. The first section introduces this study, presenting its origin, purpose and context. The second section explores the reasons behind choosing constructivist grounded theory for exploring this area and the third section provides a brief synopsis of each chapter within this thesis.

1.1. Origin, purpose and context of this study

During the first six months of my studies, I carried out a general literature review. Despite the vital role that paid social care workers play in supporting people with learning disabilities there is a paucity of empirical evidence surrounding the experiences of staff supporting tenants with cancer in

residential services. Evidence suggests people with learning disabilities are living longer, are increasingly experiencing age related illnesses such as cancer, and have poorer health than the general population (Emerson and Baines 2012). This information, together with my review of the findings from Mencap (2004, 2007), identifying the unequal healthcare that people with learning disabilities often receive from healthcare professionals, helped me to identify a gap in current knowledge. In conjunction with the wider evidence concerning the difficulties people with learning disabilities experience with healthcare, (Emerson 2010, 2012) this provided me with an opportunity to develop an important and original contribution to knowledge.

Whilst this study does not focus specifically on older people with cancer, evidence suggests the incidence of cancer is age related and will continue to increase within this population (Davies and Duff 2001). With people with learning disabilities expected to access mainstream health services (Forbat and McCann 2010), previous studies have highlighted the difficulties people with learning disabilities have accessing such services due to issues such as poor communication and stereotyping (Emerson 2010, 2012, Lennox, Lantman et al 2012, Heslop, Blair et al 2013). These factors give rise to inequalities in health. The UK healthcare system relies on individuals recognising they have a health problem, seeking assistance and reporting symptoms so that a diagnosis can be made (Emerson, Baines et al 2012).

As people with learning disabilities may experience difficulties articulating their health problems and navigating this system, they may become reliant

upon carers, including paid social care staff, to access healthcare services on their behalf (Melville et al 2005). Little is known about how paid social care staff, who may have little or no healthcare training, experience the development and ongoing challenges of supporting tenants with cancer, despite their pivotal role as the interface between the tenants and the UK healthcare system. This study seeks to address this gap in knowledge with the aim of developing a theory grounded in practice. It will provide recommendations about ways of improving practice, contribute to the development of appropriate educational programmes, and may inform policy development. It aims to assist in enabling current and future paid social care staff to be better prepared and supported within this crucial and increasingly common aspect of their work and to improve quality of service provision for people with learning disabilities. This study will focus on the situation of paid social care staff within residential services in Wales; however, the results will also be of interest more broadly both nationally and internationally.

1.2. Using constructivist grounded theory

With a paucity of research exploring this area, it was inappropriate to introduce a hypothesis. To provide a thorough foundation to explore participants' experiences, this study adopted a qualitative paradigm and a symbolic interactionist perspective. After considerable exploration and deliberation of other research methodologies such as phenomenology and ethnography (see chapter 2, page 74), I decided to employ grounded theory

methodology for this study based on its ability to address my research area and based on its flexibility and the interest it can induce for the researcher. I opted for Charmaz's (2010) version of constructivist grounded theory. This is interpretive and subjective and based on a flexible guide rather than a set of principles and practices. Epistemologically, constructivism highlights the subjective inter-relationship between the research participant and the researcher, emphasising their shared creation of meaning (Mills, Bonner and Francis 2006). It embraces the researcher's experiences in the research process, aiming to minimise any imbalances of power between researcher and research participant. By involving the researcher in the research process (and contrary to other versions of grounded theory) (Glaser and Strauss 1967, Glaser 1972) the researcher's theoretical sensitivity becomes fundamental to the process. This not only provides some flexibility concerning the much debated positioning of the literature review within grounded theory (Glaser and Strauss 1967, Glaser 1978) but having already spent six months exploring the literature, it would have been difficult to ignore the theoretical sensitivity I had already obtained. With the foundations of constructivist grounded theory embedded in relativism and its appreciation of the multiple truths and realities of subjectivism, it attempts to create an empathetic understanding of research participants' meanings making its explanatory strengths extremely powerful (Charmaz 2010). This power highlights the main issues in the research and allows others such as researchers and policy-makers to identify with the theory and use it or modify it in their own areas (Charmaz 2010).

Having had no prior contact with residential services or staff supporting people with learning disabilities, there was some discussion with my supervisor concerning whether this might impact positively or negatively on my forthcoming experiences and interpretations. On the one hand it was considered positive, as I had no preconceived ideas and therefore, no prejudice concerning services and/or staff. On the other hand negative, as I had little comprehension of the challenges services and staff negotiated on a daily basis. I felt that having limited prior knowledge was to my advantage. It allowed me to take an untainted look at my surrounding environment and eliminated my concerns of bias. Also by having no preconceptions and expectations, my initial contact with participants was interesting and exciting. Whilst I was nervous, so too were many of the research participants and upon reflection, this may well have helped balance any power differential between researcher and research participant as at times my lack of previous exposure and experience left me feeling vulnerable. Having the opportunity to put my research into practice, after months of preparation, and study the subtle nuances in research participants' attitudes and behaviours was fascinating and helped me to immerse myself further into the research area and setting. In keeping with the guidelines informing constructivist grounded theory (Charmaz 2010), I decided it would be useful to keep and review a reflexive journal during this study. Having the opportunity to reflect on my thoughts, feelings and attitudes allowed me to consider many aspects of my research journey in depth. Reflexivity has allowed me to scrutinise my research experience, my interpretations and decisions and connected me directly to the research process. It hopefully has also allowed the reader to

assess how and to what degree my assumptions, interests and positions may have influenced inquiry.

1.3. Organisation of the thesis

This thesis has eight chapters and is predominantly written in the third person. Where personal reflection is included within the body of this work, it is identifiable by the use of the first person. Within the thesis, the use of terms to describe paid social carers/paid social care staff/workers are interchangeable with the terms, 'support staff'/workers and 'social care staff/workers'.

Initially a review of the existing literature is provided. The literature review provides background and context to the research study presented in this thesis. It provides an overview of learning disability, including issues surrounding service provision, age and health, cancer and learning disability and explores the work and policy context of paid social care staff in the UK supporting people with learning disabilities. It identifies the gaps in current knowledge and outlines the aims of this study.

The methodological considerations that inform the research design of this study are then considered. The origins and foundations of social research and its epistemologies and ontologies are critically discussed. The

methodological approach chosen is then explored and the methods used discussed. An original framework of evaluation criteria is presented.

This study's findings are then presented, the emerging theory is discussed and the findings synthesised. The theoretical categories of role identity, role ambiguity, role emotions and role resolution are presented and their implications and relevance to the theoretical framework of the core category, 'building resilience' are demonstrated.

Finally the methodological strengths and limitations are explored and an evaluation of this study utilising an original framework of evaluation criteria specifically designed for this purpose is discussed. The original contributions to knowledge are outlined and the study recommendations for policy and practice are then presented.

CHAPTER 1

Literature Review

This literature review provides the background to this study. Initially it will explore the positioning of the literature review in grounded theory studies and then it will discuss the placing of the literature review within this study. The next section will critically discuss the definition of a learning disability, the incidence of learning disability in the UK, the demographic structure of this population, the process and impact of the 1970s deinstitutionalisation movement, health inequalities and ageing within the learning disability population. The incidence and prevalence of cancer and the challenges that people with learning disabilities experience living with cancer, will then be explored. The last section will focus on paid social care staff and their role. It will provide an update of the changing policy context in which staff must operate and explore the health and social care divide. This chapter concludes by outlining the gaps identified in current knowledge and discusses the aims of this research study.

There is a divergence of views concerning the position of the literature review within a grounded theory study (Charmaz 2010, Bryant and Charmaz 2011). The key tenet of the debate relates to the core issues surrounding the

controversy between Glaser and Strauss, the founders of grounded theory. Glaser and Strauss (1967) and Glaser (1972) recommend the literature review should occur after the data analysis has been completed thus ensuring the data analysis is not contaminated by prior knowledge of the area. Whereas Strauss and Corbin (1990) suggest prior knowledge of a research area is inevitable. Whilst the original assertion from Glaser and Strauss (1967) and Glaser (1972) remains popular with some scholars (Henwood and Pidgeon 2003), the latter view is supported by others (Bulmer 1979, Layder 1998 and Dey 1999) and has probably become more popular as a result of the requirement for grant and/or research proposals where study aims and objectives require prior identification. Considering this and the initial exploration of the literature, I decided to provide a preliminary literature review to position this study. A second review of the literature informed by theoretical sampling, is reflected in the 'Findings and Discussion' presented later in this thesis. By presenting a preliminary literature review I am able to demonstrate my understanding of relevant works within the research area and reveal how I identified the specific focus of this study and its original contribution to the research area. 233 sources were identified using the following search strategy:-

1. Databases – CINAHL, MedLine, ASSIA, Embase, Nursing Collection, PsycInfo, Index to Theses.
2. Search terms (used singly and in combination) – LEARNING DISABILITY*, intellectual disability*, intellectual impairment, developmental disability*, developmental delay, cognitive disability*,

cognitive impairment, mental handicap, mental retardation, mental sub-normality. DEINSTITUTIONALISATION, community living, residential settings. CANCER, incidence of cancer, prevalence of cancer, cancer management, pain management, cancer care, cancer and quality of life, health related quality of life, (types of: breast, gastric, bone, oesophageal, stomach, bowel, ovarian, testicular, skin, liver), cancer awareness, diagnosis, truth-telling, disclosure, screening, prevention, health promotion, primary healthcare, secondary healthcare, treatment, post-operative care, reconstructive surgery. ILLNESS, health, illness, terminal illness, end of life care, palliative care. CARERS, paid carers, formal carers, informal carers, support workers, institutional care, care homes, residential settings, residential homes, nursing homes, older people's homes, supported living, supported housing. AGEING, longevity, older people, ageing in place, age related illness, ageing and cancer. SOCIAL CARE POLICY, health policy, health and social care policy,

3. Dates – the initial focus of the search was from 1990 to 2010. This twenty year period was chosen to ensure a thorough search of the existing literature occurred, although where relevant, earlier and later materials were used to build the context of the review.
4. Hand searching of relevant journals and the bibliographies of identified articles also identified further papers.

The search strategy provided a wealth of literature and sometimes resulted in two or more search terms being combined. For example, '*ageing and*

cancer’ and *‘cancer, palliative care and people with learning disabilities’* provided relevant literature and valuable insight into these topic areas. Additionally the searches that did not involve the term learning disabilities or research where people with learning disabilities were not involved in the research provided a good basis on which to compare literature and issues between people with learning disabilities and the general population. For example literature exploring *‘palliative care’* provided valuable sources and insight into the issues surrounding palliative care for the general population and served to inform and highlight the differences in issues when exploring literature surrounding *‘palliative care and people with learning disabilities.’*

Table 1 Relevant literature inclusion and exclusion criteria

NUMBER	INCLUSION CRITERIA
1.	The research is ethical.
2.	The research is relevant.
3.	The research is clear and coherent.
4.	The methodology is appropriate and rigorous.
5.	The research addresses potential researcher bias.
6.	The research recognises the importance of validity.
7.	The research recognises the importance of reliability.
NUMBER	EXCLUSION CRITERIA
1.	If the language is not English
2.	If research is not a journal, research report, article, book, policy and guidance.
3.	If there is insufficient detail to identify reference.

As the literature review should be based on the best quality evidence available (Bell 2005) literature was selected using the literature inclusion and exclusion criteria above (see table 1). These criteria were developed for use in this study and in conjunction with the search strategy outlined on the previous page.

Each item has been catalogued using EndNote bibliographic management software. This database is fully searchable by, for example, keywords,

authors, journals and year of publication. It has been continually maintained throughout the study (August 2010 – January 2014 inclusive) and forms a useful resource for all relevant parties. The database will be used to inform the development of literature-based papers for publication.

1.1. Learning disability

1.1.1. What is a learning disability?

Defining a learning disability is complex and can be confusing. There are a variety of different terms in use including '*learning difficulty*' or '*developmental disability*' as well as some unacceptable out of date terms such as '*mental handicap*' (Foundation for People with Learning Disabilities 2013a). In the UK the term '*learning disability*' was introduced to replace the term '*mental handicap*' (Emerson and Heslop 2010). However, this term may mean different things to different organisations and people both nationally and internationally. For example, in Canada, Australia and the USA, the term '*intellectual disability*' is commonly used and in the USA the term '*learning disability*' is used to refer to people with specific learning difficulties such as dyslexia (Heslop et al 2013). More recently the term '*intellectual disability*' has also been adopted in the UK. For example, in the study conducted by Mansell (2010) exploring services for people with learning disabilities, the term '*intellectual disability*' was used (Mansell 2010). Accordingly Emerson and Heslop (2010) suggest that within the UK the

terms '*learning disability*' and '*intellectual disability*' should be considered interchangeable (Emerson and Heslop 2010).

In the UK many people with learning disabilities prefer the term '*learning difficulty*' (British Institute of Learning Disabilities 2011). Some carers and families of people with more complex needs, argue this term does not always reflect the level of support some individuals need (Foundation for People with Learning Disabilities 2013a). Confusion also exists surrounding the term '*learning difficulty*' as it is sometimes used to describe dyslexia and dyspraxia particularly within education services (Emerson and Heslop 2010, Foundation for People with Learning Disabilities 2013a). Within the UK people with specific difficulties in learning such as dyslexia do not have '*learning disabilities*' (Emerson and Heslop 2010). For example, Mencap use the term '*learning difficulty*' to describe dyslexia as they state that unlike a '*learning disability*', dyslexia does not affect intellect (Mencap 2013).

Some people with learning disabilities may have sensory and/or physical impairments and neurodevelopmental disorders such as autism (Emerson and Heslop 2010). They may have an increased incidence of medical problems such as epilepsy, cerebral palsy, hypothyroidism, visual impairment and hearing deficit (Gilberg and Soderstrom 2003). A learning disability is not a psychiatric disorder or a medical condition (Schalock et al 2007) and individuals who have these conditions are only included in the group of people with learning disabilities if they also have a learning disability (Emerson and Heslop 2010).

General cognitive function testing is one factor used to help determine whether an individual has learning disabilities with those with an IQ score less than 70 usually considered to have learning disabilities (Heslop et al 2013). In 1905 Binet and Simon developed the first psychometric test in France for the purpose of school placement. This was followed by a gradual acceptance of intelligence quotients (IQs) being used to measure intelligence (Gilberg and Soderstrom 2003). Over the past 35 years, there has been a significant change in the conceptualisation of learning disabilities, which are often defined or categorised using intelligence quotients such as mild (IQ 50-70), moderate (IQ 35-49), severe (IQ 20-34) or profound (IQ <20) (BILD 2011). These categorisations are sometimes considered insufficient, as they do not provide an assessment of social functioning and communication skills, physical and/or sensory impairments (British Institute of Learning Disabilities 2012). Whilst there is no general definition of intelligence, the English government's White Paper, *'Valuing People: a new strategy for learning disability for the 21st century'*, (2001) provides the most widely cited definition of a learning disability. It states that a learning disability includes:-

'a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood, with a lasting effect on development' (DH 2001:14).

The World Health Organisation's International Classification of Disease (ICD-10) definition of learning disability is broadly consistent with the UK

government definition, although it also still uses the outdated and, to some, offensive term of '*mental retardation*' (Emerson and Heslop 2010). Interestingly both of the factors outlined in these definitions may affect an individual's ability to access appropriate healthcare.

Within the majority of the literature accessed for this study, the use of the term '*learning disability*' is largely interchangeable with the American, Australian and Canadian term of '*intellectual disability*'. Whilst this term is increasingly common within the UK, for the purposes of this study the term '*learning disability*' will be used.

1.1.2. The current incidence and prevalence of learning disability in the UK

There are approximately 1.2 million people in the UK with a mild or moderate learning disability and another 210,000 people with a severe learning disability (Lodge et al 2011). Although it should be noted the validity of the study by Lodge et al (2011) may have been compromised as only seven of the 11 GP partners returned the verified lists of patients with learning disabilities and these had not actually used standardised definitions of learning disability severity. The precise incidence of people with learning disabilities within the UK population is unknown (Emerson et al 2012, Mencap 2013) and is further complicated by the difficulty in detecting

learning disability at birth. The exact prevalence of learning disability is also unknown. If applying IQ as an indicator of learning disability, current calculations of the prevalence of learning disability based on those known to social services within the general population with an IQ < 70 equates to two to three per cent of the population (Gates and Ioannides 2005). As many people with learning disabilities are unknown to social services, there is also a significant hidden population (Emerson and Hatton 2008).

Emerson et al (2001) state those with moderate to severe learning disabilities equate to three to four persons per 1000 of the population and those with mild learning disabilities are estimated to lie between 25-30 persons per 1000 of the population. Based on these calculations, 230,000-350,000 people with severe learning disabilities and 580,000-1,750,000 people with mild learning disabilities are living in the UK with males having a slightly higher rate of mild and severe learning disabilities overall (Gates and Ioannides 2005). This is largely due to genetic causes with males having only one X chromosome resulting in a gene mutation on the X being more likely to have an effect in males rather than females (Tarpey et al 2009).

As this study is Wales centric, the total number of people with learning disabilities registered with the local authority as using services aged over 16 in Wales is 11,803 (InfoBase Cymru 2012). This figure does not account for those under the age of 16 and those who are not registered with social services as having a learning disability. Jancar (1990) and others (Hogg et al 2001, Davies and Duff 2001, Janicki et al 2003, Emerson and Hatton 2008)

suggest the number of people with learning disabilities across the UK will increase significantly as they enjoy increasing longevity concurrent with the rest of the UK population. The proportion of older people in Wales has risen over the past 25 years and is estimated to continue rising in the future (Welsh Government 2004). Whilst the Welsh population is projected to increase by only three per cent, the number of people of retirement age will increase by 11 per cent and those aged 85 and over are expected to increase by over one third to 82,000 (Public Health Wales 2013). It therefore seems possible that the number of older people with learning disabilities living in Wales may increase and with the correlation between ageing and cancer widely recognised, it is perhaps fair to predict the number of older people with learning disabilities living with cancer may also increase. This information ensures research in this area is relevant and vital if Wales is to meet the changing needs of its citizens.

1.1.3. The history of and changing philosophy surrounding learning disability and service provision

Understanding the history of learning disability and the changing philosophies surrounding disability and service provision is vital to understanding the timeliness and relevance of this study. The move from institutional care to community based care was dictated by the changing

philosophies surrounding disability (Nirje 1980). This model of care, alongside increased autonomy of people with learning disabilities to make their own decisions concerning their lifestyles has resulted in people with learning disabilities increasingly living in community settings where they are supported by paid social care workers (Bhaumik et al 2011). This move has also resulted in people with learning disabilities being expected to access mainstream healthcare making people with learning disabilities responsible for the decisions they make concerning their health (Beadle-Brown et al 2007). Whilst these changes have contributed to the empowerment of disabled people, they have also raised a range of complex issues including increasing health inequalities compared to the general population and issues surrounding their mental capacity to make healthcare decisions (Alborz et al 2005). These issues are relevant to this study as many social care workers are increasingly expected to articulate and navigate healthcare and services on behalf of their tenants.

Historically people with learning disabilities were viewed within the medical model of disability and as a result have suffered and continue to suffer oppression (Oliver 1990). The medical model of disability adopts the view that disability is an illness and the result of a physical condition intrinsic to the individual requiring a medical response. This restricts the individual's quality of life by creating disadvantage and social degradation and promotes the view that a disabled person is dependent and needs to be cured or cared for (Oliver 1990). The medical model of disability remained unchallenged until the 1960s when Bengt Nirje developed the principle of normalisation in

Scandinavia. During the 1970s and 1980s the principles of normalisation underwent a variety of modifications from Scandinavia, to the USA, Australia and then back to Europe. During this period Wolfensberger (1983) developed an interpretation of the Scandinavian model linked with the USA civil rights movement encouraging service philosophy to create, support and defend valued social roles for people who were at risk of devaluation (Wolfensberger 1998).

Normalisation came to dominate the UK agenda during debates concerning services for people with learning disabilities during the 1980s. By the late 1980s cracks in this consensus became evident. Bayley (1991) argued that the valuable characteristics of individuals were not being supported within the normalisation principle, enshrining conformity rather than unconditional acceptance of differences (Chappell 1997). Others, (Baxter et al 1990, Brown and Smith 1989) highlighted that the social norms the principle of normalisation adhered to, were not objective but socially constructed and as such could serve to reproduce discrimination. Notwithstanding, Brown and Smith (1992) adopted a pragmatic approach, concurring it was the best model available and should be used as a starting point when considering issues such as service provision. The principle of normalisation had a significant impact on the way services for people with disabilities were developed within the UK and over the past forty years, disabled people have continued to challenge the medical model and the impact it has had on their lives. This has resulted in the development of the social model of disability (Culham and Nind 2003).

The social model of disability locates disability as a range of societal barriers rather than an intrinsic characteristic of individuals (Barnes, Oliver and Barton 2002). Disability is the product of the organisational, attitudinal and physical barriers within society. These foster discrimination by creating barriers to education, information and communication, working environments, health and social support services, communication systems, transport and housing (Thomas 2002). This is further compounded by the devaluation of disabled people through negative images in the media (Oliver 1990).

Within the social model of disability, disabled people should have the same opportunity as anyone else to determine their lifestyles. Despite the application of the social model being predominantly focused on physical/sensory impairment and not learning disabilities, it has made fundamental changes to the way in which all disability is regarded and has had a major impact on anti-discriminatory legislation in the UK and beyond (Chappell 1997). Despite this, discrimination remains, particularly within the fields of mental health and learning disabilities (Emerson 2010).

Amidst these changing philosophies, further questions were raised concerning service provision for people with learning disabilities. The Report of the Committee of Enquiry into Mental Handicap Nursing and Care (Jay Report 1979) introduced fundamental changes in service philosophy for people with learning disabilities. Amongst its many recommendations, the report advocated the discontinuation of learning disability nurse training and endorsed the emergence of social care workers (Sheerin 2005), who would

form one generic, and commonly trained body of residential care staff. This recommendation encouraged learning disability nurses to examine their roles and defend their unique contribution to supporting people with learning disabilities. In reality whilst learning disability nursing was not eradicated, the report changed the face of learning disability nursing in the UK. It acted as a catalyst in the development of community nursing by meeting the needs of people with learning disabilities in the community rather than institutions (Barr 1996). As people with learning disabilities moved into community settings, they required social care support with their everyday tasks rather than full-time nursing care. They were now expected to access mainstream healthcare for their health and nursing care. This has resulted in many people with learning disabilities becoming reliant on family members and/or paid social care workers to assist them in accessing healthcare (Brolan et al 2012).

Despite the increased use of residential care staff as set out in the Jay Report (1979), learning disability nursing has remained a vital aspect of learning disability service provision. This has been particularly important in view of the recent failures to meet the health needs of the learning disability population (Mencap 2007, Local Government Ombudsman 2009). Whilst learning disability services advocate the retention of learning disability nurses, uncertainty exists surrounding the boundaries of their roles and the roles of residential care/social care staff (Mitchell 2004). This uncertainty may cause confusion for both paid social care workers and healthcare staff who may be unsure who is responsible for providing healthcare support to

people with learning disabilities. In the recent Confidential inquiry into premature deaths of people with learning disabilities report (CIPOLD) (Heslop et al 2013) a lack of awareness of the roles and responsibilities of different organisations and professionals and how they might provide healthcare support was highlighted. Findings reported how some hospital staff were not aware of the differences between supported living schemes, residential care homes and nursing homes. This sometimes led to an individual being discharged from hospital with inadequate healthcare support and with paid social carers being under-equipped to deal with a person with illness. This lack of awareness and inadequate provision has worrying implications for both the quality of care provided to the tenant (Seaward 2004) but also for the mental health of paid social care staff (Brown et al 2003, Todd 2004). In a study of learning disability staff perspectives (n=64) of caring for people with learning disabilities at the end of life, conducted in Dublin by Ryan et al (2011), paid social carers agreed they wanted to provide palliative care to their tenants. In this study, data was collected through the use of 12 focus groups and staff reported they had not considered the possibility of caring for people with learning disabilities at the end of life beforehand and did not think their current training had adequately prepared them. Arguably this study could have been strengthened, by additionally exploring the wider experiences of staff providing general healthcare to their tenants. With the emergence of the social care role during the 1970s, deinstitutionalisation and the ageing demographic, residential services are increasingly confronted with issues relating to their tenants' healthcare needs. This may create ambiguity and confusion surrounding the paid social

care worker role and impact on the tenants' increasing need for healthcare support. (See appendix 1, for a timeline of the history of learning disabilities).

1.1.4. Deinstitutionalisation

Alongside the introduction of the normalisation principle and the change in learning disability nursing provision, UK society moved from institutional models of care. Long-stay institutions started to close in an attempt to promote social inclusion and community living. This societal change is commonly known as the deinstitutionalisation movement (Bennett and Morris 1983, Bhaumik et al 2011).

Whilst the majority of people with learning disabilities have always lived in the community rather than in institutions (Lindsay 2002), within the UK and more widely, developed countries, the deinstitutionalisation movement of the 1970s significantly increased the number of people with learning disabilities living in the community (Traustodottir and Rice 2009, Sheerin and McConkey 2008). In 1970 the number of people with learning disabilities living in hospital accommodation in England and Wales was 64,173. This figure fell to 6,404 by 1998 (Braddock et al 2001). Within both Wales and England, community settings are free standing homes but vary in size. In Wales they accommodate up to four tenants and within England some

homes are considerably larger, accommodating up to six tenants. Both settings accommodate tenants with a variety of learning disabilities and are often guided by a social care model characterised by a strong commitment to active social engagement (Traustodóttir and Rice 2009, Kim et al 1999). In the UK, residential settings are managed within the public, private and voluntary sectors. Pathways into residential settings differ. Some tenants were relocated directly from large institutions whilst others moved from their parents' home. Many people with learning disabilities remain in the family home until parents are no longer able to support them, at which time they either live independently or relocate to residential settings for the remainder of their lives (Windley and Chapman 2010, Webber et al 2010).

The effects of deinstitutionalisation measured against an improved quality of life have largely resulted in positive outcomes (Bhaumik et al 2011). Increases in adaptive functioning, greater opportunities and independence have been reported (Kim et al 2001, Emerson et al 1999). So too have increases in social contact and social activities (Emerson and Hatton 1996, Stancliffe and Lakin 1998, Emerson et al 1999). Deinstitutionalisation has not created positive outcomes for all with some people with learning disabilities experiencing bullying within their localities and loneliness (Forrester-Jones et al 2002), damage to their homes and greater risk of exploitation by some members of the general public (Emerson et al 2001).

The move to community living has also resulted in people with learning disabilities moving from institutionally based healthcare to mainstream health

services. Within the institution, trained nurses providing direct care often identified health issues quickly and general practitioners and specialists such as psychiatrists were allotted dedicated time to tend to their patient's needs (Bhaumik et al 2011). Since deinstitutionalisation, evidence suggests people with learning disabilities expected to access mainstream health services experience difficulty accessing such services (Alborz et al 2005) and experience significant health inequalities when compared to the general population (Emerson 2012). These difficulties have serious implications for older people with learning disabilities who increasingly require the same age-related healthcare services as other adults (Thompson et al 2004, Traustadottir and Rice 2009, Webber et al 2010).

1.1.5. Ageing

The National Framework for Older People (DH 2001) predicted that by 2025 the number of people living beyond 90 would have doubled since 1995. The World Health Organisation suggests this trend is predominantly due to social improvements and advances in medical science (WHO 2012).

Ageing affects us all and is predominantly associated with chronological age. These boundaries are becoming increasingly blurred due to changes in our socio-economic conditions, such as having the choice to take early or late retirement. Traditionally, the pensionable age is above 65 years (Connell

and Pringle 2004), although over the last decade there have been increases to the UK state pension age. International policy describes chronological age as a 'crude tool' for identifying needs of particular groups and undermines the valuable contribution older people make to society (United Nations Population Fund 1998). Leeson (2004) suggests that healthcare expenditure and mortality is increasingly linked to diet, behaviour and lifestyle and not to chronological age. More recently ageing is conceptualised in terms of the life cycle (WHO 2012). This approach is far more appropriate for people with a learning disability as they may not meet the traditional definitions of old age if ageing is defined by social, physical and psychological factors.

1.1.5.1. Ageing and people with learning disabilities

People with learning disabilities are living longer and reaching old age (WHO 2012, Jeevanandam 2009, Janicki 2009, McCarron and Lawlor 2003). Compared to the general population, they die younger (Heslop et al 2013), although longevity within the learning disability population is rising faster (Llewellyn 2009). This is the direct result of social and medical advances (WHO 2012). In England alone, it is estimated that the number of people with learning disabilities within the >50 age range will increase by 53% between 2001 and 2021 (Emerson and Hatton 2008).

As the learning disability population ages, beside their sometimes multiple pathologies, they will also become vulnerable to age-related health problems (Bigby 1998, Bland et al 2003, Janicki et al 2003), such as cancer and dementia. They may also experience different biological aspects of ageing compared to the general population. For example, people with Down's syndrome may start to show signs of decline associated with ageing in their 30s (Zigman 2002) and those with severe or profound disabilities generally tend to have a reduced longevity (Holland 2000, Rice and Robb 2004). Older people with learning disabilities are more likely to have a sensory impairment (Emerson et al 1999), which can result in difficulties in understanding activities, objects and words. Health complications related to lifestyle such as obesity are also common in older people with learning disabilities (Emerson et al 1999).

Table 2 Examples of syndrome-specific health problems

Syndrome	Syndrome specific condition	Author
Down's Syndrome	Congenital heart defects	Pueschel and Pueschel (1992)
	Gastrointestinal problems	Pueschel and Pueschel (1992)
	Visual and hearing disorders	McVicker et al (1994)
	(related to old age)	
	Infections	Marino and Pueschel (1996)
	Decreased longevity	Janicki et al (1999)
Fragile X	Mitral valve prolapse	Sreeram et al (1989)
	Musculoskeletal problems	Davids et al (1990)
	Early menopause	Conway et al (1998)
	Epilepsy	Ribacoba et al (1995)
Prader-Willi	Obesity related:	
	Diabetes	Greenswag (1987)
	Heart conditions	Lamb and Johnson (1987)

Source: Glover and Ayub 2010

Syndrome-specific conditions may also result in increased vulnerability to age related illnesses (Glover and Ayub 2010). For example, people with Down's syndrome are at a higher risk of developing Alzheimer's disease prematurely (Ward 2012). Table 2 above provides some examples of syndrome specific health problems some people with learning disabilities may experience.

1.1.5.2. *Service provision for older people with learning disabilities*

Bigby (2010) suggests, as citizens with equal rights, people with learning disabilities should receive the same support for an active and healthy old age as the rest of the population (Bigby 2010). Social policies should reflect this whilst taking into account their specific changing needs and requirements (Bigby et al 2010). In reality these expectations often remain unmet both within the learning disability population and the general population (Bigby et al 2010). The ability to age in place, choice participation, autonomy and access to care informed by the principles of rights for all older people in UK society are not always identified clearly within care standards and/or regulations (Bigby et al 2010). Even when they are, criticism exists that the emphasis on active and successful ageing might be counterproductive and oppressive (Holstein and Minkler 2007). Holstein and Minkler (2007) suggest the bodies of old people can be ignored if focus is continually placed on the positive features of ageing and those unable to meet these positive features will be devalued. Walker (2002) further recognises these strategies can be coercive, despite his commitment to active ageing policies. The United Nations Convention on the Rights of People with Disabilities (2006) has highlighted the importance of supported decision-making for people with learning disabilities to facilitate and support these goals.

The health needs of older people with learning disabilities have a significant impact on service provision and ultimately their quality of life. The World Health Organisation (2000) expressed their concern that people with a learning disability are at particular risk and state:

“In many nations, older adults with severe and profound impairments are disregarded or institutionalised. Housing is often inadequate and health provision neglected. Older adults with mild impairments are often marginalised and not provided with minimal supports needed to be productive members of their societies” (WHO 2000:3).

Ironically despite there being common goals, experiences and challenges between disability service provision and services for older people, both disabled and older people services are segregated and for those who are ageing with a disability, this poses significant challenges (Butcher 2009). In response to these challenges, Bigby (2002) recommends a specific policy direction for people ageing with a learning disability. Bigby (2004) suggests including the promotion of equal rights and choice, with disability services adopting a leadership role and any gaps being systematically filled between services (Bigby 2004). Others (Rusinowitz 1999, Priestley and Rabiee 2002) suggest a common agenda should be developed between the two services. Whilst policy directives aim for improvements in care (DH 2001), and a number of good practice guidelines are in place, such as those relating to the personal health action plan (HAP) in England, person-centered plans (PCPs), (DH 2001) and the use of communication aids such as vignettes;

improvements are slow to materialise. Evidence suggests (Thompson and Wright 2001, Hussein and Manthorpe 2005) there is much to do in providing older people with learning disabilities with the appropriate support they need. Age related illnesses such as cancer present unique challenges to both service provision and the support carers provide and it is vital these challenges are met if the quality of life of people with learning disabilities is to be enhanced.

1.1.6. Health inequalities and people with learning disability

People with learning disabilities experience health inequalities from a young age (Emerson et al 2012) and compared to the rest of the population (Elliott, Hatton and Emerson 2003, Emerson and Baines 2010). Despite life expectancy increasing for people with learning disabilities, they continue to have a shorter life expectancy and are three times more likely to die young than the general population, particularly those with Down's syndrome and those who are women and/or young adults (Emerson et al 2012).

The leading cause of death amongst people with learning disabilities is coronary heart disease and the incidence is expected to increase as people live longer (Hollins et al 1998). Approximately 50% of children with Down's syndrome experience congenital heart defects (Herman et al 2002). Forty-

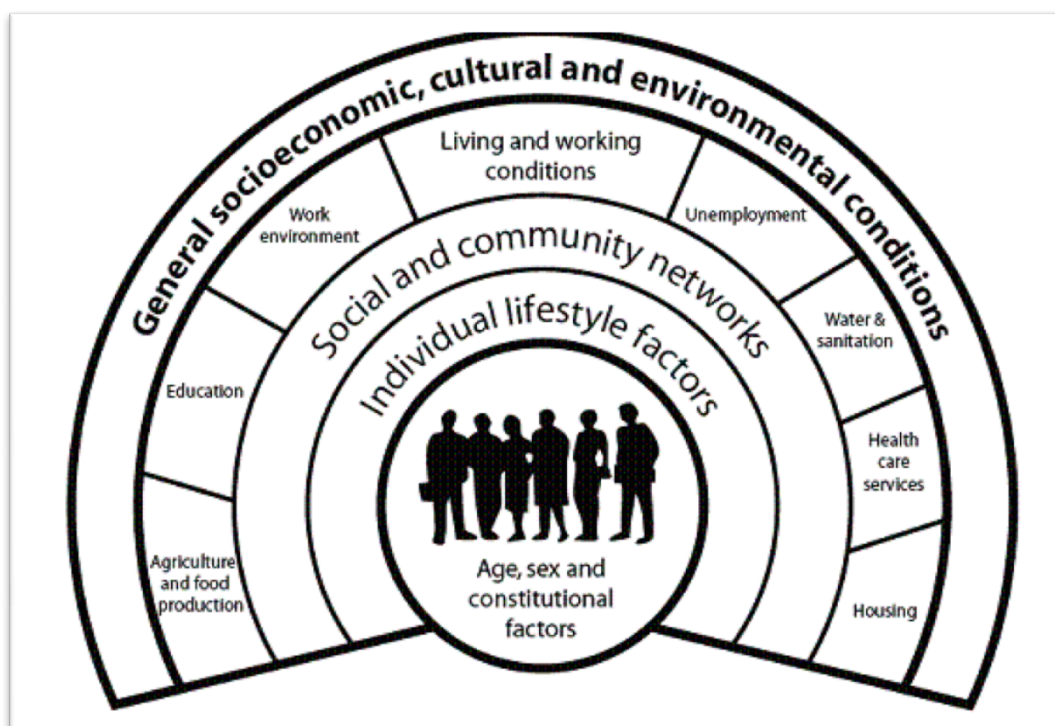
six per cent to 52% of the learning disability population compared to 15%-17% of the general population die from respiratory disease. Endocrine disorders such as hypothyroidism and diabetes also have a significant impact, with hypothyroidism common amongst those with Down's syndrome and rising with age (Gibson et al 2005). People with learning disabilities also present with increased rates of diabetes type 1 and 2 (Glover et al 2012). They are fourteen times more likely to suffer with musculo-skeletal impairments and may have a lower bone density and increased prevalence of osteoporosis (Jaffe et al 2005).

In the UK alone, 15,000 people with learning disabilities are registered blind and approximately 50,000 have a visual impairment (Emerson and Robertson 2011). People with Down's syndrome are more likely to develop vision and hearing loss and approximately 40% of people with learning disabilities have a hearing impairment (Emerson and Baines 2010). People with Down's syndrome are at higher risk of developing dementia than the general population and are experiencing symptoms 30-40 years younger (Holland et al 1998). Epilepsy is 20 times higher in the learning disability population (Glover et al 2012). Sleep disorders, mental health issues, poor oral health, gastro-oesophageal reflux disease and constipation present significantly higher rates within the learning disability population and in some cases are interlinked with other health issues. For example, people with learning disabilities may be more likely to take drugs for other health conditions that may have side effects such as constipation (Emerson et al 2012).

1.1.6.1. *Health determinants*

Determining the conditions of health in any population is complex and includes social and economic conditions as well as genetic inheritance (WHO 2013). Following the publication of the Black Report (1980) and the Whitehead Report (1987) exploring health inequalities in the UK, interest in the impact of social conditions on health started to gather pace and in 1991 the Dalgren and Whitehead model was developed (see figure 1 overleaf).

Figure 1 The Dalgren and Whitehead model



Source: Dalgren and Whitehead 1991

This model differentiates between social factors and the individual. The inner layer of the model suggests individual lifestyle factors such as physical activity and diet partly determine health followed by the next layer suggesting working and living conditions such as employment and housing also relate to health. The final, outer layer suggests the broader socio-economic, cultural and environmental conditions combine to impact on health. According to Emerson and Baines (2010) people with learning disabilities are more vulnerable to the social determinants of health such as poor housing conditions, unemployment and poverty and these social determinants directly impact on the quality of health.

1.1.6.2. *Discrimination and people with learning disabilities*

People with learning disabilities sometimes experience discrimination including institutional discrimination (Mencap 2013). This is where organisations and their workforces fail to provide services appropriate to individuals' differing needs and are ignorant and prejudiced towards those differing needs (Barnes et al 2002).

Discrimination impacts on people with learning disabilities' general socio-economic, cultural and environmental conditions and directly affects their access to social institutions such as education, employment, housing, healthcare, political participation and their right to autonomy (Barnes et al 2002). This in turn exposes them to a range of social determinants of poorer health such as social exclusion, violence, victimisation, poor housing conditions, unemployment and poverty (Emerson and Baines 2010). Whilst a plethora of UK and wider legislation (1995 and 2005 Disability Discrimination Acts, 2010 Equality Act, UN Convention on the Rights of Persons with Disabilities 2006) have attempted to tackle this discrimination, a lack of respect and understanding surrounding people with learning disabilities remains (Mencap 2013).

1.1.6.3. *Social networks and lifestyle factors*

Evidence suggests (Office for National Statistics 2013) the closer the social networks and connections people have to each other and their communities, the better health they will experience. Yet 31% of adults with a learning disability have no contact with friends and 58% of adults with learning disabilities have infrequent contact with their families. This is generally attributed to a lack of money, fear of going out, being ill and problems with travelling (Emerson et al 2012).

Since deinstitutionalisation people with learning disabilities are able to make choices concerning their lifestyles including choices relating to their diet and exercise (Emerson and Baines 2010). There is a lack of accessible dietary information for people with learning disabilities, a lack of knowledge by carers and restricted food options within residential services as a result of the necessity to accommodate more than one person at meal times. These issues have resulted in the majority of people with learning disabilities not eating a balanced diet (Emerson and Baines 2010). On average they take lower levels of exercise than the general population and are more likely to be overweight or obese (Robertson et al 2000, Kerr et al 2003, Emerson 2005). Recent trends within the general population indicate the number of overweight and obese adults in the developing world has almost quadrupled to around one billion since 1980 with the highest increases being seen in countries with rising incomes such as Egypt and Mexico (Overseas

Development Institute 2014). Arguably this could indicate that where individuals gain greater freedom of choice over their lifestyles, having the freedom to adopt an unhealthy lifestyle is not specific to the learning disability population. An exploratory, descriptive study, which used a postal service design and a questionnaire was conducted by Hanna et al (2010) from the University of Ulster, Northern Ireland. This study explored staff knowledge of cancer prevention and health promotion for people with learning disabilities. Findings indicated social care staff were well placed to encourage and empower tenants to adopt healthier lifestyles provided they receive staff education and training in health promoting activities. Whilst this study conducted by Hanna et al (2010) involved collecting data from a sample (n=40) in a specific geographical location, its findings are similar to previous studies (Mencap 2004, Peate and Maloret 2007, Taggart et al 2010).

1.1.6.4. Access to healthcare

In the past decade, the Disability Rights Commission have emphasised the issues surrounding inadequate healthcare for people with learning disabilities (Disability Rights Commission 2006). In 2001, the English government White Paper, 'Valuing People' highlighted the need for change in service provision for people with learning disabilities (DH 2001). A large number of reports and research have followed highlighting problems in accessing healthcare (Elliott et al 2003, Sowney and Barr 2004, Webb and Stanton 2009, Emerson and Baines 2010, Emerson 2012, Brown et al 2012). These include access

to primary and secondary healthcare services, low uptake of health checks, health screening and promotion activities, discriminatory practice by healthcare staff and diagnostic overshadowing (where symptoms are attributed to the nature of the learning disability rather than the illness). There are also poor or a lack of treatment options, and poor patient outcomes (Emerson and Baines 2010, Disability Rights Commission 2006, Mencap 2004, 2007, 2009).

In 2010, a survey of 1000 healthcare professionals found that almost half of doctors (45%) and a third of nurses (33%) admitted that they had personally witnessed a patient with a learning disability being treated with neglect or a lack of dignity and 39% of doctors and 34% of nurses stated that people with learning disabilities are discriminated against in the NHS (Mencap 2010). Although in a survey conducted by Hatton et al (2011), investigating reasonable adjustments being made for people with learning disabilities within English NHS Trusts, researchers were able to identify examples of good practice and positive and innovative signs in providing reasonable adjustments.

Despite recommendations to improve access to healthcare such as the hospital passport tool (a passport providing information relating to the person with learning disabilities to help improve communication) (Bell 2012), annual health checks, information provided in easy read format (Jones et al 2007), improvements to the physical environment and flexible appointment systems both within primary and secondary healthcare settings (Backer et al 2009);

significant difficulties and inequities remain (Emerson 2012). People with learning disabilities are already increasingly reliant on paid social care staff to support them in accessing health services, to act as their advocate within healthcare settings and/or to provide their home-based healthcare generally (Melville et al 2005, Kyle et al 2010). Advocacy seeks to ensure that individuals are able to express their views and defend their rights. There are many different types of advocacy including case, self, peer, paid independent, citizen and statutory advocacy (British Institute of Learning Disabilities 2009). Within this study the term 'health advocate' relates to an individual who seeks to ensure the person with learning disabilities is able to express their views and concerns, access information and services, defend and promote their rights and responsibilities and explore their choices and options in regard to their health.

These difficulties and inequities concerning access place further reliance on social care workers to articulate and navigate these challenges on the tenant's behalf. Some of these challenges relate to issues of consent and therefore it is important that social care workers understand the implications of the Mental Capacity Act (2005).

1.1.6.5. The Mental Capacity Act (2005)

Mental capacity means having the ability to make decisions. There was no clear legislation on mental capacity in England and Wales prior to the Mental

Capacity Act (2005) (British Institute for Learning Disabilities (BILD) 2009). Individuals who lacked capacity had no legal protection and their family members and/or carers had no legal rights. If possible, their only option was to plan for their future loss of mental capacity (BILD 2009). The Mental Capacity Act (2005) was introduced to allow individuals to make their own decisions based on their ability to do so, rather than others' assumptions about their level of capacity and ability (BILD 2009).

Health issues are complicated for people with learning disabilities by poor use of and poor understanding of the Mental Capacity Act (2005) (Heslop et al 2013). Within the healthcare environment, the appropriate use of the Mental Capacity Act (2005) has raised considerable concern regarding low levels of compliance amongst healthcare staff and confusion concerning the process of gaining consent from the person with the learning disability (Dunn et al 2008). A study conducted by Skinner et al (2010) identified that whilst the expectation following the introduction of the Mental Capacity Act (2005) was to enhance competence and confidence in assessing capacity amongst staff, ironically it has had the opposite effect. Whilst this study acknowledges a degree of confusion and contradiction surrounding its study sample, the recent CIPOLD report also identified concern surrounding both the adherence to, and understanding and implementation of, each of the five principles of the Mental Capacity Act (2005) by both healthcare and social care staff (Heslop et al 2013).

As this study focuses on the experiences of paid social care staff supporting tenants with cancer, the findings from the above studies may have implications for this study. Where social care staff support tenants through initial symptoms of cancer/illness, diagnosis and treatment pathways, having a clear understanding and correctly implementing the principles of the Mental Capacity Act (2005) is vital to the welfare of their tenants and their civil rights as individuals. The individual concerned can only give consent. If the individual is assessed as lacking capacity to make that specific decision then a best interests decision has to be made on their behalf. A lack of capacity should be determined as a result of assessing the person's capacity in accordance with the Mental Capacity Act (2005) and its Code of Practice (Ministry of Justice 2014). The Act does not define what is meant by 'best interest' although a 'best interest checklist' is provided as a guide. It should involve where possible, the individual, their family, friends and carers (Foundation for People with Learning Disabilities 2013b). It should also include (where known) the individual's known wishes. In relation to healthcare, however, the clinician is the ultimate decision maker having taken account of all of this information (Ministry of Justice 2014).

1.2. Cancer

Cancer is not a single disease. There are over 200 different types of cancer that require a variety of treatments (Macmillan 2013). It is a leading cause of

death worldwide and the incidence of cancer rises dramatically with age (World Health Organisation 2013). Currently, one in three people in the UK receive a cancer diagnosis within their lifetime and more than one in four people will die of cancer (Tuffrey-Wijne 2010). In 2008, 27% of all deaths were due to cancer in the general UK population and 76% of those deaths occurred in people aged >65 (Cancer Research UK 2010).

1.2.1. Learning disability and cancer

The incidence and prevalence of cancer within the learning disability population is complex and information concerning survival rates is lacking (Hogg and Tuffrey-Wijne 2008). Evidence suggests people with learning disabilities have higher levels of gastrointestinal cancers such as stomach, oesophageal and gallbladder and those with Down's syndrome are at a higher risk of lymphoblastic leukaemia (Cooke 1997, Hardy et al 2011). Lifestyle factors such as limited cognitive function, limited mobility, poor diet, weight gain, smoking and unemployment, increase the risk of cancer in people with learning disabilities (Baxter and Bradley 2008). There is some debate concerning the incidence of cancer in people with learning disabilities, (Forbat and McCann 2010, Hanna et al 2010) and a lack of research exploring the incidence and prevalence of cancer within this population. Current research suggests that it is lower than in the general population (12-18% within the learning disability population against 26% in the general population) (Emerson and Baines 2010, McIlpatrick et al 2011). The reasons

for this are not known and it may be attributed to lower incidence or lower detection rates. However, compared to the general population, people with learning disabilities have proportionally higher rates of gastrointestinal cancer (48%-59% versus 25% of cancer deaths) (Jancar 1990, Duff et al 2001).

The correlation between ageing and cancer is already established (Lamont et al 1990). This, juxtaposed with deinstitutionalisation and the increased emphasis on the rights of people with learning disabilities to make lifestyle choices that may impact on their health and increase their risk of cancer (Hogg and Tuffrey-Wijne 2008), will almost certainly increase the incidence of cancer within this population (Emerson and Baines 2010).

There is a history of research highlighting the challenges experienced by people with learning disabilities living with cancer (Cooke 1997, Hogg et al 2001, Forbat and McCann 2007, Hogg and Tuffrey-Wijne 2008, McEnhill 2008, Tuffrey-Wijne and Bernal 2009, Tuffrey-Wijne et al 2010, Hanna et al 2010, Tuffrey-Wijne et al 2011, McIlpatrick et al 2011, Michelmores 2012). Key issues include a lack of knowledge and accessible information relating to cancer and prevention for people with learning disabilities. For example, health promotion information relating to health screening may not be in a format that is accessible (Hanna et al 2010). Whilst the study conducted by Hanna et al (2010) was collected from a small sample in a single geographical location, other studies, (Mencap 2004, Taggart et al 2010) have drawn similar findings. However, improvements to increase accessibility and

knowledge relating to cancer and prevention for people with learning disabilities are being made (Jones et al 2007, Change 2011).

Incorrect assumptions may be made by service providers regarding the lifestyle choices of people with learning disabilities which may result in a low uptake of cancer screening (Baxter and Bradley 2008). For example, there is a poor uptake of cervical screening in women with learning disabilities as it is sometimes wrongly assumed that they are not sexually active and are at a lower risk of cervical cancer than the general population (Wood 2007, Baxter and Bradley 2008). People with learning disabilities also have poor access to primary healthcare services such as GP surgeries and are at a high risk of diagnostic overshadowing (Gibson 2006).

There is a lack of experience and/or confidence among medical and healthcare staff such as GPs, oncologists and nurses, in providing people with learning disabilities with the support they need during their experiences of cancer (Forbat and McCann 2007). People with learning disabilities are at risk of experiencing discrimination surrounding treatment options (Tuffrey-Wijne et al 2009), which may leave them vulnerable to a poor prognosis.

People with learning disabilities living with cancer may find it difficult to communicate symptoms of illness and pain, which may result in a late cancer diagnosis and/or restricted treatment options (Stanish et al 2006). For example a literature review carried out by academics in the US and Canada,

report difficulties in communication such as obtaining patient consent may impact on the investigation of early symptoms or latterly, treatment options (Stanish et al 2006).

The cancer diagnosis itself sometimes depends on someone noticing something is different and/or wrong and decisions surrounding disclosure of the diagnosis, prognosis, and treatment options are generally taken or influenced by family or paid social care workers (Tuffrey-Wijne 2009). A lack of facilities, staffing levels and training of social care staff within residential settings to support a tenant with cancer, remain key challenges (Cass et al 2009).

The majority of challenges people with learning disabilities and cancer experience seem to relate to a lack of accessible information and poor communication. Family and social carers, either paid or informal, play a vital role in facilitating access to these by providing the pivotal interface between the person with learning disabilities and society at large. Paid social care workers play an increasingly vital role in supporting their tenants with cancer. The next section of this literature review will discuss the social and economic conditions of this workforce, the challenges they face and the changing policy context in which they operate.

1.3. Paid social care staff in the UK

The current number of people employed as adult social carers within the UK is 1.85 million. Eighty-two per cent of the workforce is female and 82% are British nationals. The average age of a social care worker on starting is 35 years old, with 13.5% aged 50 or over and one third being over 40. More than 50% of the current workforce has been employed in social care for over six years (Skills for Care 2013a).

This study focuses on the experiences of paid social care staff employed within Wales. Across the UK, social care staff are among the lowest paid and least qualified in the UK labour market (Low Pay Commission 2010, TOPSS 2000). According to a recent report: State of the Adult Social Care Sector and Workforce in England, Skills for Care (2012), in England alone approximately 150,000 workers in the social care sector may be getting paid less than the minimum wage. There has been a 1.7% decrease in wages since 2010 (ONS Annual Survey of House and Earnings 2012).

1.3.1. Paid social care staff supporting people with learning disabilities

Paid social care staff working with people with learning disabilities are required to promote increased competence in daily living skills and facilitate participation in a wide range of daily living and community activities with their tenants (Bratt and Johnston 1988, Duker et al 1989, Felce and Perry 1995). For example, staff undertake a range of roles including food preparation and service, domestic duties and administration (Elliott et al 2003).

When this study commenced in 2010 the quality of support people with learning disabilities received from paid social care staff was largely dependent on individual service provider philosophies and settings. Generally, those that promoted individuality, participation and independence seemed to be the most successful (Felce and Perry 1995). More recently there has been considerable concern relating to the quality of care provided in residential and nursing homes across the UK (Care Quality Commission 2012). There have been several scandals involving the neglect and mistreatment of vulnerable adults including the abuse that took place at Winterbourne View private hospital (DH 2012), Hillcroft nursing home (BBC 2014) and Ash Court residential nursing home (Panorama 2012). In consideration of this, the ageing population and increasing demand for social care, the government is currently reviewing social care policy (DH 2013, National Assembly for Wales 2014).

1.3.2. Changing social care policy context

Approximately 70% of the social care workforce have undergone and completed induction training. Induction training programmes have been introduced across the UK and offer an initial 12 week structured and recorded assessment induction for social care workers that is relevant to their workplace and their role (Skills for Care 2013b, Care Council for Wales 2013). This was followed in March 2013 with the introduction in England by the Department of Health of a Code of Conduct and Minimum Training Standards for adult social care and healthcare workers (DH 2013). Wales and across the rest of the UK had already introduced a Code of Conduct and a Code of Practice prior to this. The demand for adult social care to support an ageing population between 2010 and 2025 is estimated to increase from 24% to 82%. There is also concern relating to the quality standards of care following the aforementioned scandals. As a result and despite ongoing concern from government surrounding containing costs, enforcing quality standards within the sector has become a government priority.

Timely to this study, at the time of writing, the Social Services and Well-being (Wales) Bill is at Stage Three of the legislative process and currently being considered by the National Assembly for Wales (National Assembly For Wales 2014). The Bill is expected to become statute later in 2014. This Bill aims to address key challenges faced by public services in Wales in view of the continuing challenging economic situation and demographic changes such as the increasing ageing population. It aims to integrate health and social care more fully, ensuring vulnerable people are protected more effectively by considering the extension of the range of services available by

direct payments, and the introduction of a national eligibility criteria based on individual need. The introduction of this Bill was followed by the publication of a paper on the future of social services in Wales by the Welsh government. 'Sustainable Social Services for Wales: A Framework for Action' (Welsh Government 2013a) outlines a framework for meeting the challenges facing social services over the coming decades. It sets out its priorities, which include the Welsh government taking greater responsibility for the direction of services and the social care workforce receiving more support. It also ensures service providers are accountable for the quality and safety of the services they provide and drives improvement within service provision in a more coherent way (Welsh Government 2013a). In England a Commission (Commission on the Future of Health and Social Care in England) is currently taking place to review the ways in which health and social care are organised and funded (Kings Fund 2013).

The current changing policy context is particularly relevant to this research study. It will provide insight into the current experiences of paid social care staff supporting tenants with cancer and evidence of how these staff are undertaking basic healthcare tasks they may be ill equipped to provide. It may also help to highlight the ways in which social care workers in Wales should be trained and supported in this relatively new dimension of their roles.

1.3.3. Health and social care divide

Historically within the UK government Department of Health, health and social care services have been divided both in terms of service provision and in terms of funding. Divisions have also existed within the culture of health and social care services with social services and the third sector being valued differently than the health service (Unison Cymru 2013). This outdated model of care founded on the post-war settlement has led to criticisms of ineffective joint working practices, with claims that it often falls short in providing the support individuals need (Kings Fund 2013). In consideration of the UK's ageing population estimates have forecast the number of people over 85 will double over the next twenty years and their need for both health and social care provision will significantly increase. This will place further pressure on both health and social care services and emphasizes their need to work more effectively together (DH 2013).

The UK and Welsh governments aim to integrate health and social care services and provide integrated services that work successfully together. They plan to provide the best and most cost effective care available and based on an individual's circumstances. In England following the Health and Social Care Act (2012), plans are in progress to implement these changes by allocating councils and healthcare organisations financial budgets to integrate their health and social care services over the next three years. At the same time they are also giving individuals personal health budgets to

purchase the health and social care services they require. Personal budgets may well give people with learning disabilities more control over their health and social care service provision. Although they also raise serious questions concerning their access to independent advocacy support to help them understand their options and budget. Information relating to personal budgets and services will need to be available in an easy read format, and the budget they are given must be sufficient to meet their needs (Mencap 2012). The integration of health and social care services would appear in principle to be a sensible move both financially and from a more co-ordinated service perspective. Although in reality there will need to be greater integration of these funding streams (Mencap 2012) and the commitment of staff to the aims and outcomes of new joint working partnerships will need to be secured as it will be crucial to its success (Cameron et al 2012). An electronic database will be created to provide patient information that can be shared across health and social care services (DH 2013). In Wales a framework for delivering integrated health and social care for older people, 'Delivering Local Health Care' (Welsh Government 2013b) is currently under consultation and complements the framework for developing community services. The aims of these frameworks alongside The Social Services and Well-being (Wales) Bill are broadly similar to the aims outlined by the English government to integrate health and social care services and provide more effective and person-centred health and social care provision in the future.

1.3.4. Challenges for paid social care staff supporting people with learning disabilities

Following deinstitutionalisation and the increasing ageing population social care workers are increasingly being expected to provide care as well as support in their daily tasks (Ryan et al 2011). As previously discussed, the social care role has predominantly been one of facilitating independence and promoting autonomy for residents and tenants (Black and Hyde 2004). The role of providing care is more health related, requiring a different approach. Traditionally, caring is a central value in professional nursing (Staden 1998, Bolton 2001). In the UK, decisions to make nursing an all-graduate profession have gathered pace over the last decade with many healthcare assistants continuing to work under the direction of a registered nurse. In contrast whilst social work has also become a graduated profession, social care workers are not required to work under the direction of a social worker. They work independently and are not required to have any formal qualifications. With social care workers increasingly being expected to provide healthcare support and the type of care that has previously been the central role of nursing, serious questions concerning social care workers current capacity to provide this type of support need to be considered. Whilst many social care workers are prepared and willing to take on these extra and quite different responsibilities (Todd 2004, 2013, Ryan et al 2011, Wiese et al 2012), service organisations do not seem to have addressed this new dimension of their roles. Current social care workers job descriptions do

not appear to incorporate, outline or recognise these new 'care' orientated tasks, (see appendix 6), and current staff training provision does not always provide relevant training (Ryan et al 2011, Wiese et al 2012). Additionally, service organisations do not seem to have considered the emotional impact providing this type of care can have on staff (Todd 2004, Ryan et al 2011, Wiese et al 2012). This fundamental change in the social care role alongside the lack of recognition of these changes by service organisations may have a significant impact on both the quality of care received by tenants and the needs of social care workers as they attempt to meet the changing needs of their tenants.

1.4. Summary

This review of the literature has demonstrated that people with learning disabilities are living longer, making them vulnerable to age related illnesses such as cancer. Concurrent with the philosophy surrounding the social model of disability and following deinstitutionalisation, larger numbers of people with learning disabilities are now living at home with ageing relatives or in residential settings within the community and are expected to access mainstream healthcare services. Within the community, a social-care model characterised by a strong commitment to active social engagement often guides the support they receive. Despite being citizens with equal rights, people with learning disabilities experience significant health inequalities

compared to the general population. With the correlation between ageing and cancer already established, the incidence of cancer within the learning disability population seems likely to increase and many residential settings may be confronted with higher numbers of tenants with cancer. This poses significant challenges for paid social care staff that are amongst the least qualified and lowest paid in the UK. These staff have little or no healthcare training but are increasingly being expected to support tenants with cancer. Currently there is a paucity of research exploring their involvement and experiences in these challenges despite their pivotal role. To reduce further risk to both staff and tenants, research is required to explore the involvement and experiences of these staff and make useful recommendations to improve the current and future situations they encounter.

1.5. Aims and objectives of this study

Little is known about the experiences, challenges and support needs of paid social care staff supporting people with learning disabilities living with cancer in residential services across Wales. The aim of this study is to explore these issues in depth. The information gained will be used to provide a better understanding of the experiences and challenges paid social care staff currently face, gain a better understanding of their support needs in this regard and to inform future policy, educational and practice development in this area.

This study has the following objectives: -

- To explore the experiences of paid social care staff, including their understanding, involvement, participation, practice and exposure to people with learning disabilities living with cancer.
- To explore the challenges arising from supporting people with learning disabilities living with cancer, such as the issues that confront staff with difficulty and/or success.
- To explore the support needs of staff working with tenants living with cancer.

These objectives will be addressed using Charmaz's (2010) version of constructivist grounded theory, the rationale for which is set out in the next chapter.

CHAPTER 2

Methodology and Methods

This chapter consists of four sections and will address the methodological considerations that inform the design of this research study. As this study is based within the social sciences and adopts a qualitative paradigm it is relevant to discuss the foundations of social research. This alongside the reasons why a qualitative paradigm was chosen will be presented. The second section will discuss the meaning of methodology. An exploration of ethnography and phenomenology will follow. Grounded theory and its various dimensions will then be critically discussed. Constructivist grounded theory will be examined and a rationale presented for its use in this study. The third section will discuss the research design and the methods used to conduct this study and will include issues surrounding sampling and recruitment, ethical considerations and conducting fieldwork. Finally in section four research evaluation criteria will be considered and the development of an original framework of evaluation criteria for use with constructivist grounded theory will be presented.

2.1. Social research: its epistemologies and ontology

Within the social science arena, qualitative and quantitative research paradigms differ with respect to their epistemological foundations. An epistemological foundation consists of a theory of knowledge, its validation and the methods it uses to make sense of the world (Keeney 1983). Within social science research there are two main epistemological positions; *positivism*, a position that advocates the application of the methods of the natural sciences to the study of social reality using quantitative research methods, and *interpretivism*, a position requiring a comprehension of the subjective meaning of social action using qualitative research methods (Sarantakos 2005). In the quest for knowledge, each epistemological position attracts a specific ontology such as *objectivism* within the quantitative paradigm and *constructivism* within the qualitative paradigm (Bryman 2004).

It was not until the 1960s that the hegemony of positivism was seriously challenged by post-positivists such as Cicourel (1964), Schutz (1962) and Garfinkel (1967) and others who were the proponents of social theories such as symbolic interactionism, (practiced by members of The Chicago School), philosophical hermeneutics (developed by Gadamer), Marxism, (developed by Marx and Engels and later practised by others at the Frankfurt School), feminism, phenomenology (developed by Husserl and Schutz), and ethno

methodology, (pioneered by Garfinkel) (Walliman 2005). They argued that the scientific model and/or quantitative paradigm was not an appropriate model for studying people and the human experience (Cohen et al 2007). By the late 1960s and throughout the 1970s sociologists and anthropologists adopted the qualitative paradigm using qualitative methodology such as grounded theory, ethnography and phenomenology, within the research arena which had previously been dominated by positivism and the quantitative paradigm (Sarantakos 2005).

Positivism is still the dominant public model for research (Ryan 2006). This dominance has been further fuelled by the development of evidence-based practice. Evidence-based practice is founded on positivist epistemology and assumes a new way of gaining healthcare knowledge. By promoting the collection, interpretation, and integration of valid clinician-observed, patient-reported and research-derived evidence, it seeks to assess the strength of evidence of risks and benefits of healthcare treatments, thus aiming to improve clinical judgments and facilitate cost-effective care (Peile 2004). According to Ryan (2006), positivist dominance has two overarching effects; namely it leads to an assumption that to conduct social research 'properly', it must follow the model of the natural sciences; and secondly, by fostering this idea, it rejects research as a valuable tool in understanding the rich complexity of social life as it is deemed inadequate to explore social lives. For example, it is ineffective in exploring how individuals view the world, live, make changes and cope with their everyday lives.

In contrast qualitative research seeks to provide an in-depth picture, interpreting culturally and/or historically significant phenomena. It requires the researcher to grasp the subjective meanings of social action. It is inductive, in that theory is generated from the research and does not require a hypothesis to test, it concentrates on smaller sample sizes than quantitative research and its ontology is based on constructivism. Constructivism asserts social phenomena and their meaning, are continually being accomplished by social actors (Bryman 2004).

The interpretive paradigm was chosen for this study predominantly based on these criteria. It relies on people's words as its primary data, valuing participants' perspectives on their worlds. This provides an effective arena for the researcher to ask difficult and sensitive questions that cannot be answered precisely. It also provides an appropriate way to explore the sensitive and sometimes emotive issues surrounding cancer. It relies on naturalistic approaches to inductively and holistically understand human experience in context-specific settings and attempts to understand and explain a phenomenon, rather than search for external causes or fundamental laws (Remenyi et al 1998). A positivist approach would not be appropriate for this study as there is no hypothesis to test, data cannot be collected objectively and a positive approach would not allow for an in-depth picture to develop.

2.2. Methodology

A methodology is a series of choices about what information and data to gather and how to analyse this information and data (Backman and Kyngas 1999). It is a systematic attempt to explore the best way to solve the research problem under investigation. It is the logic behind the methods selected to explore the research problem, and provides an explanation of the reasons why particular research methods have been chosen over and above other research methods. This allows the research findings to be evaluated by the researcher and others. For example, what data have been collected and why has a particular technique been used to analyse that data? This section will discuss ethnography, phenomenology and the different versions of grounded theory. It will then explore the choice to use constructivist grounded theory within this study.

2.2.1. Ethnography and Phenomenology

Ethnography refers to both a method and a written product of research based on that method. The researcher participates in people's daily lives and collects data by using participant observation and other sources such as interviewing and gaining as many relevant documents to the research topic as possible. It can be overt or covert and relies heavily on field notes to prompt the ethnographer's memory (Hammersley and Atkinson 2010).

Multiple data collection methods can be used to explore and collect data relating to one single phenomenon including surveys, observational data, recordings, and photographs. One of the main issues surrounding the use of ethnography involves obtaining and maintaining access to the data (Feldman et al 2003). It can be labour intensive. Participating overtly or covertly in people's daily lives can be extremely complex and challenging to navigate (Hammersley and Atkinson (2010). This is particularly so when considering the ethical issues surrounding accessing vulnerable groups such as people with learning disabilities. It has also been criticised for interpretations being value laden (Borman et al 1986). For example, as a result of its reflexive nature where the researcher is viewed as part of the world that is under study and is therefore affected by it, the researcher's interpretations may not be an objective reflection of the research phenomena. Whilst ethnography can produce deeply rich data, knowing when to stop collecting data can also be challenging due to its unstructured nature (Bryman 2004). Whilst some proponents of ethnography would argue leaving the field is determined by a strong sense of déjà vu towards the end of data collection (Altheide 1980), unlike Glaser and Strauss's (1990) grounded theory approach, in ethnography there is no indication for the researcher to be sure there are no new questions to be asked and no new comparisons to be made (Bryman 2004).

Phenomenology is considered both a philosophical perspective (for those who adhere to the descriptive approach developed by Husserl (1962) and the interpretive approach developed by Heidegger (1962)), as well as a

qualitative methodology (for those who adopt the position put forward by Schutz (1967)). Arguably this has resulted in its development being viewed as controversial and often confusing particularly within the social sciences (Rehorick and Taylor 1995).

It is the study of phenomena, their meanings and nature (Finlay 1999). It involves defining a research question and gathering deep and rich data from a sample through participant observation, interviews and discussions (Aspers 2005). In the past sample sizes have been small (<5) (Smith and Osborn 2003, 2008) although more recently, sample sizes have ranged from one to thirty-five with the majority of studies falling in the middle of this range (Brocki and Wearden 2006). Phenomenologists often seek guidance from existential philosophers whilst interpreting their data and through data analysis they hope to discover the deeper meaning of the “lived” experience in terms of the research participant’s relationship with time, space and personal history (Stern, 1994). Data collection and analysis are also specifically prescribed. Intense reflection is an integral part of the phenomenological process although the primacy of the subjective experience is considered to be crucial. Meaning units describing the key aspects of the experience are formulated by scrutinising the text during analysis. These are synthesised to create a general description of the “whole”. In the past some have often questioned the validity of findings based on its small sample size (Jasper 1994). Analysis can also be problematic predominantly because of the vast data it generates.

In summary, I rejected ethnographic methodology as I did not consider it to be the best approach to address the study aims and objectives. For example, I considered it ethically unsound to observe staff whilst providing care for their tenants who had cancer. Additionally it may not have provided the depth of information surrounding their experiences of providing this support. Additionally, ethnography presents difficulties accessing and maintaining access to the field, attracts criticisms claiming it can be value laden as the researcher becomes so immersed in the field and lastly as a result of its' relatively unstructured nature, it can be difficult to know when to stop collecting data. I rejected phenomenological methodology because whilst it might have allowed me to describe an experience, it may not have been particularly helpful in seeking to improve practice. Additionally I rejected phenomenology because of the confusion often surrounding its' different uses and approaches and the need to define a research question prior to entering the field.

I rejected Glazer and Strauss' approach to grounded theory as I had already obtained significant theoretical sensitivity before entering the field. I rejected Strauss and Corbin's approach, as I did not want to attempt to minimise the theoretical sensitivity I had already obtained and I wanted to incorporate my experiences as the study researcher into the research process. As a result and after considering a variety of methodologies, constructivist grounded theory appeared to be the most appropriate methodology for use in this study. This decision will be discussed in depth in the following sections.

2.2.2. Grounded theory

Grounded theory was developed by Barney Glaser and Anselm Strauss and published in their seminal and sole collaborative publication in 1967, '*The Discovery of Grounded Theory: Strategies for Qualitative Research*'. Grounded theory emerged at a time when the scientific community viewed qualitative methodology suspiciously and favoured quantitative/positivist research (Boychuk Duchscher and Morgan 2004). Glaser (1978, 1992) later claimed this period presented an elitist bias towards quantitative research in the generation of theory, stating that it served only to fuel the validation and verification of theory through test variables rather than actually generating theory.

Grounded theory provided a groundbreaking methodology that offered increased validity to both quantitative and qualitative analysis but took prominence within the '*qualitative revolution*' (Denzin and Lincoln 1994, p.ix). It provided traits of the popularised quantitative paradigm by being systematic and methodical but was firmly based on inductive analysis (Seale 1999, Charmaz 2000, Walliman 2005) where theories emerge inductively and are 'grounded' in the data. Today, its academic rigour is widely accepted and as a result of its dichotomous trajectory, it provides many different approaches.

2.2.3. What is Grounded Theory?

Grounded theory is inductive and based within symbolic interactionist ontology. Induction provides tentative knowledge, allowing the researcher to develop a picture of the phenomenon based on inductive reasoning (Bryman 2004). Inductive analysis is driven by the data themselves as opposed to deductive analysis where a theoretically driven hypothesis is tested. It does not necessarily follow the chronological processes of the traditional research process (Lofland et al 2006). For example, it does not identify a phenomenon, label it, collect data relating to it, analyse it and report its results and conclusion.

Symbolic interactionism starts from the concept that people interact in terms of symbols, such as language and communication. To understand human action, it is necessary to discover the meanings people use to guide, interpret and make sense of their own actions and those of others (Blumer 1969, Mead 1934). Originating from the work of George Herbert Mead, symbolic interactionists assume individuals respond towards human actions based on the meanings they ascribe to those actions. These meanings derive from the social interaction they experience with individuals and society at large and are shaped and modified through an interpretive process determined by the individual trying to understand these actions (Blumer 1969, Mead 1934). This theoretical perspective is well suited to this study as it provides an ideal

basis to explore participants' experiences and their interpretation of those experiences.

Within grounded theory, analysis and data collection are not separate phases of the research but operate simultaneously. This process is enhanced by recording data and simultaneous reflection on the data as it is collected. Constant comparative analysis is fundamental to the analysis and theory development stages of grounded theory (Glaser and Strauss 1967, Glaser 1978, Strauss and Corbin 1990, 1998, 1998a, Charmaz 2000, 2010). This involves constantly making comparisons between the data being collected, the developing codes and the categories and concepts developed during data collection and analysis (Glaser and Strauss 1967, Charmaz 2010).

Analysis initially involves coding data, encouraging the researcher to study the data closely and begin conceptualising ideas (Charmaz, 2000). Coding allows the researcher to analyse each word, line or selections of lines of data, naming actions or events. At the beginning, coding should be unrestricted, tentative and provisional but may latterly be collapsed, reorganised and re-labelled (Boyчук Duchsher and Morgan 2004). Coding begins by the researcher asking a prescribed set of questions from the data such as 'What is the situation?', 'How is the person managing the situation?' (Glaser and Strauss 1967, Glaser 1978, Strauss and Corbin 1990, 1998).

The researcher writes a series of memos to him/herself throughout the coding process, enhancing the reflection process and encouraging him/her to raise further codes to tentative categories. Memo writing allows the researcher to disassemble the codes and analyse them in memo format, providing a way to compare the data and explore ideas about the codes. Memos can then be integrated and concepts identified which may lead to the writing of the first draft of the findings. This process allows the researcher to learn how the research participants make sense of their experiences, by beginning in the first instance to make analytic sense of their meanings and actions (Glaser and Strauss 1967, Glaser 1978, Strauss and Corbin 1990, 1998, Charmaz 2000, 2010).

There are many challenges within this process. Walliman (2005) suggests the main challenge is placing the data into categories without losing their complexities and subtle inter-linkages. He suggests that the ability to practically organise data into categories whilst retaining a level of flexibility enabling exploration of the linkages, can be problematic. Others (Backman and Kyngas 1999, Annells 1997, Boychuk Duchscher and Morgan 2004) state it can be a time consuming and long process and particularly challenging for a novice researcher in view of its variety of approaches. Historically and contemporarily, grounded theory has attracted a plethora of divergent views concerning not only its differing philosophical paradigms of inquiry, but also its practical and theoretical approaches and these divergent views will now be discussed.

2.2.4. Grounded theory and its dichotomous trajectory

Glaser's past was entrenched in the quantitative paradigm which is reflected in his positivist, objective, codified methods and systematic approach to grounded theory. Contrastingly, Strauss's background was ingrained in qualitative inquiry, post-positivism and pragmatist ideology (Charmaz 2000). It was not until after Glaser and Strauss' publication in 1967, that their differing philosophical paradigms became apparent (Stern 1994). Strauss established a new affiliation with Juliet Corbin and their first co-authored works were published in 1990 highlighting their alternative approaches to grounded theory (Strauss and Corbin 1990, 1998).

Glaser criticised Strauss and Corbin's alternative approach, claiming that it was not *grounded theory* and should be renamed as a *conceptual description* (Stern 1994). Glaser (1992) condemned their approach of gaining theoretical sensitivity; namely their acceptance of preconceived ideas and the acquisition of any prior knowledge of the phenomenon before entering the field. He criticised their suggestion of theoretical sampling, (sampling based on developing theoretical categories where the researcher seeks only people, events or information to illuminate and define the boundaries and relevance of the categories), and its strict orientation towards the emerging theory as well as their coding approaches, claiming they were too complex. Glaser (1978, 1992) insisted that the researcher should not develop any form

of theoretical sensitivity prior to entering the field and should have as few preconceived ideas as possible to minimise the risk of bias in interpretation during analysis of the data (Lofland et al 2006).

Glaser (1992) accused Strauss and Corbin of 'forcing' the data rather than allowing a grounded theory to emerge, claiming that grounded theory must have 'fit and relevance'. For example, categories of theory must fit the data, the data must not be forced to fit the categories but confirmed by continual comparative analysis (Backman and Kynglas 1999). Glaser stated that whilst the researcher should be encouraged to return to the field to gain further data with which to build the theory, there should be less regard to the source of that data and more regard to its strict orientation towards the emerging theory (Glaser 1978). In contrast, Strauss and Corbin's approach to grounded theory follows the post-positivist line of inquiry, and is based on pragmatism, which in turn informs symbolic interactionism. For Strauss, subjective and social meanings rely on the use of language and emerge through action. Therefore, Strauss and Corbin (1990) suggest a degree of subjectivity is inevitable and should be accepted whilst also taking measures to minimise its intrusion into the analysis (Stern 1994).

According to Strauss and Corbin (1990) the researcher already has some theoretical sensitivity to the data and initial gathering of data prior to entering the field can only help to increase theoretical sensitivity and assist in identifying gaps in existing knowledge. They claim a second review of the literature should be woven into the emerging theory generation during the

concept development stage of the study. Whilst Glaser (1978) agrees that a second review of the literature is necessary, he disagrees concerning the timing of the second review, stating it should not be carried out until the theory has emerged (Glaser 1978, 1992). Further divergence in methods is evident between Glaser (1978, 1992) and Strauss and Corbin (1990, 1998) concerning the coding process. Fundamental to Glaser's initial process of coding he asks '*what do we have here?*' This is followed by three phases of coding; '*input*', where the data moves as part of the researcher's thinking; '*drugless trip*', where the data are in the researcher's mind; and '*saturation*', where the researcher writes the results and conclusion (Glaser 1978, 1992). Strauss and Corbin on the other hand initially ask, '*What if?*' which is followed by a complex process of coding beginning with '*open coding*', where basic categories are developed, followed by '*axial coding*', a complex process involving both inductive and deductive thinking, and then a process of reduction follows where categories and themes are reduced. Selective sampling of the literature and data to fill any gaps in the data and a process of selective coding then concludes the process (Strauss and Corbin 1990, 1998).

Approaches to coding by Glaser and Strauss (1967), Glaser (1978, 1992) and Strauss and Corbin (1990, 1998) differ extensively and have led some scholars to suggest that the complex nature of Strauss and Corbin's coding is ineffective. According to Glaser (1978), there is insufficient detail to direct a novice researcher in the process of developing concepts and limited information pertaining to the saturation of codes possibly resulting in the

researcher drifting into preconception (Boychuk Duchscher and Morgan 2004).

Interestingly following the development of Strauss and Corbin's (1990) post-positivist method, various attempts have been made to simplify the analytical process of grounded theory and rectify some of its alleged complexities and ineffectiveness (Eaves 2001, Clarke 2003, Charmaz 2010). Eaves (2001) developed the '*synthesis technique*' for data analysis. This technique lends itself to the use of qualitative software packages such as NVivo in the process of coding and the reduction of data into categories. Situational analysis (Clarke 2003) was later developed introducing a '*mapping*' technique allowing the researcher to analyse the data in greater depth whilst also recognising the importance of context and situation (Clarke 2003, 2005).

Arguably the most influential interpretation of grounded theory has been by Kathy Charmaz, a student of Glaser and Strauss and her landmark work on constructivist grounded theory. Perhaps its greatest strength lay in its foundations in relativism and its appreciation of the multiple truths and realities of subjectivism. This positioning helps to create an empathetic understanding of research participants' meanings making its explanatory strengths extremely powerful. This power highlights the issues within the research phenomena for others such as researchers and policy makers in a way that allows them to identify with the theory and use it or modify it in their own domains.

2.2.5. Constructivist Grounded Theory

Mills et al (2006) claim the embryonic stages of constructivist grounded theory can be identified in Strauss and Corbin's (1990) work on grounded theory and Charmaz (2000, 2010) has emerged as the principal advocate of constructivist grounded theory (Mills et al 2006). Constructivism is a research paradigm that denies the existence of an objective reality and asserts that,

'Realities are social constructions of the mind and that there exist as many such constructions as there are individuals (although clearly many constructions will be shared)' (Guba and Lincoln 1989, p.43).

Epistemologically, constructivism highlights the subjective inter-relationship between the research participant and the researcher, emphasising their shared creation of meaning (Mills et al 2006). According to Charmaz (2010) the constructivist grounded theory process is interpretive and subjective and does not provide a precise and literal picture of the studied world. For example, as constructivist analysis directs the researcher to theorise in the interpretive tradition, a mundane statement such as 'school is boring' may allude to a variety of meanings and experiences. For example, an individual may actually find school boring or they may consider that stating school is interesting will make *them appear* boring and less popular among their peer group. When a researcher explores tacit meanings not everyone is able to describe and link their actions to particular meanings. The researcher

develops methodological and analytic strategies, such as reflexivity, flexibility, empathy and imagination which can be applied to processes of sampling or data collection techniques to learn about relevant meanings and actions within a particular research arena (Mills et al 2006, Charmaz 2010).

Constructivist grounded theory assumes that the theoretical basis of the study is an interpretive depiction of the studied world and that research participants' experiences and meanings in conjunction with the researcher's completed grounded theories are constructions of reality. According to Boychuk Duchscher and Morgan (2004),

'it recognises the mutual creation of knowledge by the viewer and viewed and aims towards interpretive understanding of subjects meanings'
(Boychuk Duchscher and Morgan 2004, p. 606).

Researchers delve beyond the surface in seeking meaning from the data, questioning tacit meanings about values, beliefs and ideologies. Charmaz (2010) places the researcher as *co-producer* urging him or her to contribute to the description of the situation, the interaction, the participant's influences and their opinion of how the interview went. The researcher becomes a core part of the process of constructing grounded theory and this approach is contrary to Glaser's (1992) approach of an emergence model. In the emergence model, theory rises out of the data, is returned for authentication

and then rises again clear of interpretivism (Boychuk Duchscher and Morgan 2004).

Theoretical sensitivity is fundamental to the process and includes the researchers' insight into the research area. This insight may derive from personal experience within the phenomenon and may also be enhanced by the review of literature in the area under study (Strauss and Corbin 1998). Reports and correspondence can be analysed as part of this process. Review of the literature should be interwoven throughout the process assisting the researcher in their theory construction (Mills et al 2006). Data can be collected using a variety of qualitative methods, such as ethnographic approaches, interviewing, and textual analysis (Charmaz 2010).

Although coding is less complex than the Strauss and Corbin (1990) approach, constructivist grounded theory coding also begins with the researcher asking analytic questions and consists of at least two phases; initial and focused coding. Initial coding is the study of words, lines, incidents and segments of the data and may include codes of participants' own terms, also known as *in vivo* codes.

Focused coding allows the researcher to take the initial codes and test them against other data. As with the other approaches to grounded theory, comparative analysis between the codes and then the data and the codes is a continuous activity throughout the process. The emerging analysis may

then require further elaborate codes or require the researcher to move to extant theoretical codes (Charmaz 2010). As in all models of grounded theory, memo writing is core to the constructivist grounded theory approach, requiring the researcher to write about the codes and subsequent theoretical categories within the data. This process aims to expedite analytical work, accelerating productivity. It provides the link between data collection and the writing of drafts of papers (Charmaz 2010), enhancing auditability (Beck 1993). Charmaz (2010) recommends a process of 'free-writing', encouraging the researcher to write freely, alleviating the constraints of grammar and punctuation to enable the researcher to get ideas down quickly and comprehensively and in a 'natural voice'. Free writing is undertaken for a set number of minutes (eight), which increase with practice. This is particularly important in grounded theory as the theory is actually generated from the emerging data rather than from testing a hypothesis.

As tentative categories emerge, theoretical sampling allows the researcher to re-enter the field and fill any gaps in the data, until data saturation is achieved. Following data saturation, memos are sorted and integrated into the theoretical categories. Charmaz (2010) suggests that using diagrams and maps to help explain the researcher's position and direction can be extremely helpful, although unlike Clarke's (2003, 2005) situational analysis and mapping approach where all relationships mapped hold equal relevance, the use of diagrams in constructivist grounded theory does not form an intrinsic part of the grounded theory process but offers a concrete image of an idea (Clarke 2003, Charmaz 2010). This practical and visual process is

helpful to not only the researcher but also the reader in illustrating the researcher's route from data to code, code to category and category to concept.

The final process of Charmaz's constructivist grounded theory relates to writing up the research. This can generate a plethora of tensions between scholarly requirements and grounded theorising. For example, scholarly requirements historically lay in the quantitative paradigm requiring an objectivist approach based on assumed neutrality (Charmaz and Mitchell 1996). This may clash with the qualitative paradigm requiring a subjectivist approach based on interpretivism (Charmaz 2010). Charmaz (2010) developed the theme of writing as a strategy of constructivist grounded theory, stating that writing needs to be literary more than scientific and evocative of the experiences of participants. The experiences of others should be portrayed in the most faithful way possible (Munhall 2001) and should be judged by their credibility, originality, resonance and usefulness (Charmaz 2010). The cultural, historical, organisational and emotional contexts should all be considered when shifting from the analytical writing of memos and categories to the communicatory writing for an audience (Charmaz 2010).

2.2.6. Reflexivity

Reflexivity generally refers to the researcher's critical scrutiny of their own research experience. It is an exploration of their own attitudes and values within the research process and how these personal attitudes and values impact on the research process (Lynch 2000). It acknowledges the social construction of the interview and/or participant observation and is therefore, epistemologically underpinned by symbolic interactionism (Elliott and Lazenbatt 2004). It explores the researcher's interpretations and decisions surrounding their involvement in the research process, allowing the reader to assess to what extent and how the researcher's assumptions, interests and prior knowledge have influenced their inquiry (Charmaz 2010).

According to Lynch (2000), for some, reflexivity is considered as an essential human capacity, for others it is a critical act. It is often claimed as a methodological virtue providing superior insight that can enhance objectivity (Lynch 2000). For example, Cutcliffe (2000) suggests it exposes and acknowledges the researcher's prior knowledge of the research phenomena and encourages discussion concerning the impact this knowledge has on the theory development thus ensuring methodological rigour (Cutcliffe 2000). This is corroborated by Hall and Callery (2001) who suggest it enhances the rigor of grounded theory studies and suggest it can add to theoretical sensitivity during the interviewing and participant observation stages of a study as a result of the assumptions taken for granted by participants and researcher that can influence data collection. Glaser (2002) on the other hand, rejects the use of reflexivity in grounded theory, claiming it is destructive and immobilizing (Neill 2006). In contrast, proponents of

constructivist grounded theory unequivocally recommend its use claiming it demonstrates to the reader how the researcher has conducted their research and identifies how they have related to the research participants and represented them in written reports (Charmaz 2006).

As the process of reflexivity is commended in studies that utilise constructivist grounded theory, a reflexive approach has been used in this study. This may increase the reader's understanding of the research process and product and also allows the researcher to record observations about their own research process. This introspective reflection and internal conversation may help to mediate between the researcher's professional and personal life and contributes to the generation of knowledge. Whilst the study conducted by Longhofer and Floersch (2012) focuses on reflexivity in social work, they suggest reflexivity is important and affects the trustworthiness of a study by allowing the reader to question whether the researcher can be trusted and believed. They further suggest that the process of reflexivity is how the researcher develops and articulates that trust (Longhofer and Floersch (2012).

In this study, I have maintained a reflexive journal, which can be accessed through the NVivo study file (available upon request). Where it has been appropriate to include reflexive accounts of the research process, particularly at the end of each of the 'Findings and Discussion' chapters (chapters 3-6), writing has been rendered in the first person.

2.2.7. The use of constructivist grounded theory in this study

The use of constructivist grounded theory in this study ensures theory generated from data is grounded in the social care workers' experiences. This really appealed to me as I wanted to produce findings that were true to the research participants' experiences. As it was inappropriate for me to test a hypothesis, constructivist grounded theory also provided me with the ideal set of tools and significant flexibility to explore the research area freely. Whilst I accept rules and procedures can sometimes be helpful, by not having a strict set of rules and procedures I was able to accommodate the direction the research was taking, rather than shutting down avenues that did not adhere to methodological rules. For example, as a result of service organisation constraints, I had the flexibility to organise more than one interview on one particular day without contravening the rules of a particular methodology. From a practical perspective, unlike the Strauss and Corbin (1990) approach, the coding is relatively straightforward in constructivist grounded theory and provided me with an opportunity to use qualitative software such as NVivo making my data management easier. This methodology also allowed for a larger sample than that of phenomenology but smaller than that required for a survey. A survey would also have been inappropriate to use based on the limited knowledge surrounding this area. Whilst the sample size in grounded theory is determined by data saturation, this was significant as there is both a lack of data available on the incidence

and prevalence of cancer within the learning disability population and is also affected by the number of people with cancer living in these particular settings. Therefore, from the outset I was unable to estimate the number of potential research participants. However, as this was a qualitative study, if at all possible, I did not want a sample larger than twenty participants and therefore, initially started recruitment across the South Wales area only with the plan to widen the recruitment area later if I was unable to recruit more than ten participants within my initial chosen area.

Whilst I had no prior experience of, or contact with, learning disability services and/or staff before commencing this study, I had already conducted a preliminary literature review during the first six months of this study. With this in mind, I considered it impossible to remove the knowledge I had already gained and my preconceptions of the research phenomena during future data collection and simultaneous analysis. Fortunately (and one of the core reasons why I opted to use constructivist grounded theory), it provided me with the opportunity to incorporate my involvement in the research process and embraced any preconceived ideas and knowledge that may have influenced my research allowing me to reflect critically on these. A constructivist approach recognises the data and analysis as a shared creation of experiences between research participant and researcher. It acknowledges the resulting grounded theory is both an interpretation of research participants' experiences and the researchers view (Charmaz 2010). This process is further enhanced by the use of reflexivity. My involvement also helped to minimise the power differential between the

research participant and myself. This was very appealing to me, particularly as I expected participants to experience some feelings of vulnerability during the interviews as a result of discussing the emotive and sensitive issues surrounding cancer. I considered building rapport vital in gaining rich and in-depth data and also in view of the emotive and sensitive research topic where participants might be reluctant to discuss their experiences in depth.

Perhaps the greatest strength of constructivist grounded theory, lies in its foundations in relativism and its appreciation of the multiple truths and realities of subjectivism. As the approach to writing is more literary than scientific and allowed me to use raw data to illustrate my findings, I can encourage the reader to follow me beyond the surface of phenomena, questioning tacit meanings, values, beliefs and the ideologies of the social care workers. This positioning helped me to create an empathetic understanding of the research participants' meanings. This makes its explanatory strengths extremely powerful and highlights the issues within the research phenomena for others, such as researchers and policy-makers, in a way that will hopefully allow them to identify with the theory and use it or modify it in their own areas of work.

2.3. Study Research Design

By providing a framework for the collection and analysis of data, the research design reflects the decisions I have made concerning my chosen data collection and analysis tools (Bryman 2004). The chosen method of data collection for this study was semi-structured qualitative interviewing. This provided the opportunity of obtaining greater control over my data construction, opposed to other methods such as ethnography, and lent itself particularly well to the data collection and analysis stages of constructivist grounded theory (Charmaz 2010).

I elicited views concerning the participants' subjective world and experiences by undertaking semi-structured interviews. I was able to explore and obtain in-depth individual accounts of the experiences of staff supporting tenants with cancer whilst also allowing myself the flexibility of redirecting my interview questions as ideas and issues emerged during the interview process. This flexibility was important to ensure research participants' tacit meanings and beliefs were explored fully throughout the research process. Additionally, as I had no prior exposure to learning disability services, I held no preconceptions or judgements concerning the research participants' tacit meanings, beliefs and experiences.

There are a variety of interview techniques available, ranging from formal interviews such as structured, onto less formal, semi-structured and unstructured interviews. Semi-structured and unstructured interviews are the most popular amongst qualitative researchers as they provide purposeful conversations (Mason 1996). The participant is encouraged to talk at length

about a range of issues either loosely outlined in an interview schedule of topics or from an invitation for the participant to talk on whatever they feel is relevant. As the data produced is a result of the interaction between the researcher and participant, the researcher is often viewed as a co-producer of the data (Mason 1996). The reason why this approach lends itself so fittingly to grounded theory data collection is that it is the participant who directs the conversation and the issues that are discussed within the broader theme of their experiences of supporting a tenant with cancer. This data informs the selection of future participants and interview schedules through theoretical sampling. It also ensures simultaneous analysis is '*grounded*' in the data collected from these interviews. Grounded theory is the emerging theory grounded in the data. (See appendix 2 for the interview guide sheets used in this study).

Whilst interviews can be used in conjunction with other research techniques such as focus groups, I wanted to adopt a symbolic interactionist perspective and carry out an in-depth exploration of participants' experiences, to allow me to access individuals' attitudes and values in their '*own voices*' using their '*own language*'. This approach is particularly pertinent to voices, which may have been ignored or misrepresented in the past (Seale 2012). It is also conducive to constructivist grounded theory methods where the researcher aims to create an empathetic understanding of the research participants' meanings (Charmaz 2010). To ensure I understood their '*own language*' I spent time prior to the interview building a rapport with research participants. For example, we talked about how long they had worked within the

organisation, what they liked most about their jobs, whether it had been difficult to make time for the interview within their busy schedules. Additionally, during the interviews if I was unsure of the meaning of a word they used, or unsure of the experiences they were trying to impart, I asked them to explain what they meant and offer examples. This provided me with a greater understanding of *'their language'*.

2.3.1. Sample

There is a lack of information regarding incidence and prevalence of cancer which made it difficult to estimate how many social care staff would be or have been supporting a tenant with cancer living in residential settings (see page 105 for further discussion on recruitment).

Whilst a sample (n=9) of private and voluntary residential services across Wales were invited to participate in this study, only two organisations were able to take part. Two declined on the basis that they currently did not provide residential services to people with learning disabilities. Two organisations declined on the basis of a staff reorganisation and a lack of available staff time to participate in the study. Despite numerous attempts to contact over a six-month period, two organisations did not respond to any contact and one organisation did not have any potential participants. This study was therefore conducted using two residential services located across the South Wales area. The majority of participants (n=13) were employed by

one organisation. Whilst these 13 staff were employed by the same organisation, they were working in four different housing projects in different locations in Wales, supporting five tenants who had/have cancer. All fourteen research participants met the study inclusion and exclusion criteria (see box 1).

Box 1: Study inclusion and exclusion criteria

INCLUSION- the study recruited participants who were: -

1. Any member of permanent staff
2. Currently/or had supported a person with learning disabilities living with cancer
3. Employed for a minimum of six weeks
4. Supporting a tenant with cancer during the past five years
5. Within residential services operating within both the private and third sectors across Wales

EXCLUSION – the study excluded those who were: -

1. Unable to give written informed consent.

To obtain a sample is to select a portion of the population for research (Bryman 2004). My sampling strategy was based on: -

- The need for a degree of flexibility as there is a dearth of literature relating to the incidence and prevalence of cancer within the learning disability population and a dearth of information concerning the numbers of paid social care staff supporting tenants with cancer living in residential settings across Wales.
- The need to interview staff that had or were having the experience of supporting a tenant with cancer.
- The need to adhere to the methods of constructivist grounded theory.

Initially, I used purposeful sampling as I wanted to select participants who were experiencing a specific phenomena, (supporting a tenant with cancer), within a specific environment, (residential settings across Wales). According to Patton (1990) the benefits of purposeful sampling relate to being able to select the sample that can provide the most in-depth and rich information concerning the phenomena.

From this purposeful sample, I progressed to theoretical sampling. Coyne (2008) suggests theoretical sampling originated alongside the discovery of grounded theory (Glaser and Strauss 1967) where data collection and analysis operate simultaneously and inform the researcher where data should be collected next (Bryant and Charmaz 2007). Theoretical sampling encouraged me to ask additional questions of participants, (see appendix 2 for interview guide sheet 2), allowing me to refine my categories and develop my emerging theory. Interviewing research participants and selecting questions relevant to the data being collected achieved this. This data allowed me to fill any gaps in my analysis.

2.3.2. Recruitment

It is impossible to determine the sample ceiling in grounded theory as theoretical sampling ensures there can be no predetermined ceiling, only data saturation (Bryant and Charmaz 2007). However, if adopting a qualitative paradigm within a grounded theory study, numbers should be

relatively small. This is in keeping with qualitative ontology enabling the researcher to develop and explore participant experiences in greater depth (Creswell 2007). Therefore, my initial aim was to recruit no less than ten but no more than twenty participants. I contacted the chief executive officer of each of the nine organisations introducing my study and invited them to meet with me to discuss their potential participation. Two weeks later having received no responses, I contacted each organisation by telephone, requesting to speak to the chief executive officer and was told either by them or their assistant to email my letter to a specified contact (see appendix 5). I did this and again followed each email with a further telephone call.

Of the two participating organisations, Hanover and Sterling, (pseudonyms have been used), Hanover was only able to identify one tenant who had had cancer and I was able to interview one member of staff directly involved in supporting this tenant. This participant explained that whilst other staff were involved in supporting this tenant, they were unwilling to participate in this study as they were still grieving and felt the experience would be too upsetting. There were other tenants who had previously had and/or died of cancer across both of these organisations. However, these deaths had occurred over five years previously and did not meet the study inclusion criteria. Following contact with Sterling, another five tenants who had cancer were identified and I was able to interview a further 13 staff who met the study inclusion criteria and who had supported/were currently supporting these five tenants. Each tenant lived within four different housing projects provided by the same organisation, Sterling. All of the tenants referred to in

this study were over forty and whilst the correlation between ageing and cancer is recognised, it should be remembered that cancer occurs over the lifespan, even if it is not apparent within this sample.

Managers from each of the housing projects identified staff that met the inclusion criteria and contacted them directly. I provided the managers with a study information sheet, consent form and a contact sheet of organisations providing help, support and counselling (see appendix 3) which they forwarded to the relevant staff. Once the staff had received this information from their managers, I requested that staff contact me directly if they wanted to participate. Upon contacting me, I answered any questions they had relating to the study and offered to meet with them prior to the interview to discuss the study further.

Table 3 Demographic profiles of participating staff

GENDER	PSEUDONYM	AGE (APPROX)	POSITION	LENGTH OF SERVICE	PRIOR H/CARE EXPERIENCE	TENANT SUPPORTED
F	Betty	40-50	Manager	>15 years	No	Joan
F	Anna	30-40	Senior support worker	>10 years	Yes	Jim
F	Janet	40-50	Manager	>10 years	Yes	Jim
F	Sue	30-40	Manager	>10 years	No	Graham
F	Michelle	30-40	Senior support worker	> 10 years	No	Graham
F	Mary	40-50	Support worker	<2 years	Yes	Graham
M	Bob	40-50	Support worker	>10 years	No	Graham
F	May	50-60	Support worker	>25 years	Yes	Joyce
F	Vanessa	20-30	Support worker	> 5 years	No	Joyce
F	Kelly	30-40	Senior support worker	>15 years	Yes	Joyce
F	Rachel	40-40	Manager	>10 years	No	Neil
F	Tanya	50-60	Manager	>20 years	Yes	Joyce/Ben
F	Lorraine	50-60	Support worker	>20years	Yes	Joyce/Ben
F	Lorna	30-40	Support worker	> 15 years	Yes	Joyce/Ben

Table three provides a demographic overview of the research participants involved in this study and the tenants they were supporting/had supported

(pseudonyms have been used for both participants and tenants). I have also omitted the ages of the tenants and their cancer diagnoses where available, to maintain confidentiality. Interestingly, of the six tenants involved, four had a confirmed cancer diagnosis but according to participants, only two of these wanted to be informed of their cancer diagnosis. The other two chose not to be informed. Of the two that didn't receive a cancer diagnosis, one died whilst investigations were being carried out and the other died without a formal diagnosis. Their cancer diagnoses were confirmed at post-mortem. According to Heslop et al (2013) the deaths of people with learning disabilities are less likely to be reported to the coroner compared with the general population. Although when they are reported, they are just as likely to have a post-mortem. Heslop et al's (2013) study also suggests some of the deaths reviewed, should have been reported to the coroner, but were not. The size of the total sample of research participants was 14. Of these 14, 13 participants were female. In total, three participants were managers of one or more projects, three were senior support workers and the rest (n=8) were support workers. One participant had over twenty-five years of experience within the service, two had over twenty years, three had over fifteen years, six had over ten years, one over five years and only one had less than two years experience. Eight members of staff had some type of healthcare support experience prior to being employed as a social care worker. Seven of these staff had some healthcare support experience from working in former council hostels and/or institutions before deinstitutionalisation occurred. These hostels and/or institutions were run along medical as opposed to social care lines. One member of staff had healthcare support

experience from working in a nursing home for older people. All participants shared their experiences of supporting six different tenants. 12 of these staff knew and/or supported the same tenant for a period of over ten years of their working lives and, of these 12, five knew and/or supported the same tenant for a period of over fifteen years. Six participants had direct experiences of an immediate family member having been diagnosed with cancer. One staff member had a direct experience of a close friend having been diagnosed with cancer and one staff member had just received a cancer diagnosis herself and was about to embark on treatment. Of these eight staff, four suffered bereavement as a result of the cancer diagnosis.

Recruiting for this study was complex for three reasons; firstly the economic climate. Staff were reluctant to take time out from their schedules as there was insufficient staff to cover their absence and two of the nine organisations were being restructured and felt unable to dedicate the time to an external study. Secondly, historically people with learning disabilities were sometimes viewed as socially dead (Todd 2013), and over recent decades service philosophy has largely focused on enabling tenants. This has resulted in some staff finding the subject of serious illness and/or death within this setting extremely challenging (Sinason 1992, Todd 2003, 2005, 2013). Thirdly, some staff were either grieving or trying to cope with the realities of supporting a tenant with cancer and were reluctant and/or unable to revisit painful and in some cases, recent and ongoing experiences.

2.3.3. Ethical considerations

It is recognised that discussing experiences of supporting a tenant with cancer may be considered sensitive (Abrahams 2007). For this reason careful consideration was given to the ethical issues arising within this study both for the research participants and for the researcher. With the help of my supervision team, the key ethical issues were identified and discussed. These included informed consent, discussing sensitive and emotive topics, the provision of emotional support and/or counselling during and post interview and privacy and confidentiality and were similar to any research involving human subjects (World Medical Association 2000). Formal University of Glamorgan (now University of South Wales) ethical approval for the study was received from the Faculty Ethics Committee in June 2011 (see appendix 4). As all of the research participants were employed within the private sector, National Health Service ethical approval was deemed unnecessary.

2.3.3.1. *Informed Consent*

At this stage of the study, my main concern was the welfare of all research participants and to ensure they were free from any potential harm whilst considering and/or participating in this study. Part of allaying my concerns was to ensure participants knew exactly what the study was about, were

aware of what their participation would entail and knew they could suspend and/or withdraw their involvement at any time without repercussions.

As previously discussed, I provided the managers of participating organisations with the study documents. The participant information sheet outlined exactly what participation would entail (see appendix 3). This information was intended to fully inform participants of the risks involved in taking part in the study in order to enable potential participants to make an informed decision (Seymour and Skilbeck 2002). When I received contact from interested staff members I answered any questions they had concerning the study, summarised the information sheet, consent form and contact sheet for them and, if they wanted to proceed, I arranged a mutually convenient time and venue for the interview. I informed them that whilst they would not receive any direct benefit from being involved in the study, their participation might be an opportunity for them to share experiences, feelings, opinions and their knowledge (Murray 2003, DiCicco-Bloom and Crabtree 2006). Prior to commencing the interview, I again encouraged further discussion concerning the study and answered any final questions. I then requested their signed consent form, ensuring it had been signed and dated by the research participant and an independent witness.

In reality, I experienced some challenges in using the participant information sheets, consent forms and contact sheets to get '*informed*' consent. It was clear to me that many participants had not read through the study information documents and the discussions we had prior to the interview were vital in

ensuring they understood the study, how important it was for them to read and understand the documentation provided and most importantly how they could access support after the interview took place if they needed to. This is not unusual. In a study conducted by Mason and Allmark (2000) exploring neo-natal care, participants regarded the information sheets as an information source to refer to after the interview relying on the doctor to provide a verbal account of the study.

2.3.3.2. *Discussing sensitive and emotive topics*

There is a wealth of research indicating data collection around sensitive and emotive topics can cause psychological distress (for example, McCosker et al 2001, Corbin and Morse 2003). This is particularly pertinent when discussing cancer. For almost half (n=6) of the research participants, the issue of cancer was not just confined to a single exposure at work, but included exposure through personal encounters. These experiences sometimes involved family members and friendship groups. Therefore, particular effort was placed on developing effective and safe relationships with research participants. My supervision team was on hand to advise, mentor and support my aim to conduct my interviews with compassion, empathy and support and at times I accessed this resource. I recognised the potential for some participants to have personal experiences of cancer and/or death and in designing my study, I tried to develop strategies to respond to these. For example, I scheduled interviews towards the end of the working

day so participants did not have to return to work after the interview. This allowed them to go home and access support if they needed to.

Prior to each interview, I stated I was not a qualified counsellor and had no background or experience of providing professional counselling or emotional support. I ensured all participants were in receipt of the contact sheet provided. This listed providers of professional support and encouraged participants to make contact should they feel the need (see appendix 3). I reiterated at the beginning and at the end of each interview that participants should be aware that whilst they may not experience distress during or directly after the interview, a delayed reaction of distress was possible. Whilst all participants experienced some distress during the interviews and seven of the 14 participants did become very upset at various points during the interview, they all asked to continue once they had composed themselves.

Interviews were purposely not scheduled at the beginning or during a working shift and never took place at the working venue. Interviews took place at a variety of venues chosen by participants and these included the service organisation's head office and local community meeting rooms. This ensured participants had the choice of where to go at the end of the interview. As stated above, this also allowed them to access support straightaway if they needed to and meant they were not exposed to the working environment or staff/tenant after the interview. When interviews identified areas where there was a lack of information concerning cancer

services or cancer information and/or when participants directly asked for specific information, I made follow-up contact either by email or telephone and either provided a contact that could provide the information, or provided the information myself.

During the course of the study, I accepted invitations to attend social events at various projects. No data was gathered during these events. Whilst I did not encourage study related discussion at these events, these encounters provided staff with an opportunity to approach me again for further information should they have needed or wanted it. McIlpatrick (2007) and others (Seymour and Skilbeck 2002, Addington-Hall 2002) suggest these types of encounters can be conducive in reducing any post interview stress such as emotional upset. Finally no one left the interview in a visibly distressed state.

The first interview was emotionally charged and from this experience I was able to plan and prepare in advance for the subsequent interviews. For example, as we approached the end of the interviews, I warned participants the interview was coming to an end and tried carefully to steer the conversation onto less emotive topics, allowing them time to adjust from a sometimes highly emotional state to a more balanced state.

From the outset of this study my supervision team recognised that I might need support during the interview process (Dickson-Swift et al 2008,

Davison 2004, Liamputtong 2007). An emotional welfare check was arranged for me to share my experiences and feelings with a professional counsellor based within the Family Institute at the University. This enabled the counsellor to monitor my emotional wellbeing and decide whether I needed a referral for counselling. It was agreed that I would meet with her after the first two months of data collection and upon request on an ad hoc basis if and when either myself, or my supervision team felt I needed to.

2.3.3.3. *Privacy and confidentiality*

Privacy and confidentiality were an extremely important aspect of this study. Not only from the research participants' perspective but also from the perspective of the tenants they were supporting. Interviews took place at a venue suitable and convenient to the participant. All interviews were conducted in a private room where privacy and confidentiality were not compromised.

To protect the privacy of staff and ensure their interest and possible participation remained confidential from colleagues and their service organisations, staff were asked to contact me directly. This ensured I was not given staff details without their prior consent and that managers did not know who had taken part in the study. Whilst a minority of participating staff talked amongst themselves concerning their interviews and then latterly relayed some of these comments to me, they were all aware of the need to

adhere to confidentiality. The comments relayed to me demonstrated the closeness of their working relationships. I maintained my levels of privacy and confidentiality throughout and after the study.

All participating service organisations, research participants and tenants were allocated a pseudonym. This ensured the anonymity of participants and tenants. Some participants had already given the tenant a pseudonym, which I adopted when interviewing, but later changed when typing up the transcriptions. All the collected data, transcripts, field notes and any other documents relating to the study, were managed and stored securely using the University's NVivo software programme in hard drive format on a password protected computer locked in a postgraduate research students' office or my home. On completion of the study all information will be moved into the University archive storage and stored for seven years. All dissemination of the findings of this study will be anonymised to protect participant and tenant confidentiality.

2.3.4. Fieldwork

My fieldwork took place between December 2011 and March 2012. In total I conducted fourteen, one to one, in depth, semi-structured interviews which were digitally recorded and transcribed. These interviews provided me with an opportunity to explore in depth, on both a factual and interpretive level (Kvale 1996) paid social care staffs' experiences of supporting a tenant with

cancer in residential settings. The interview process consisted of four stages: preparation, taking a pragmatic approach, undertaking the interview and finishing the interview.

When the potential participant made contact with me (either by telephone or email) we arranged a convenient time and venue to meet. Many of the staff I interviewed were restricted by their schedules. Therefore, I was flexible and prepared to meet in a place convenient to them. All of the interviews were conducted during daylight hours. During the data collection period I provided my supervisor with a weekly schedule of my interview appointments and texted her to let her know when each interview was over and I had left the field in keeping with the University's lone worker policy.

In grounded theory, the process of interviewing and data analysis occur simultaneously to facilitate constant comparative analysis. This ensures that the core themes within each interview are identified and incorporated into the next interview and so on until data saturation occurs and no new data presents itself. As recruitment for this study was particularly complex for the reasons already outlined (see page 105 for further discussion on recruitment) it was necessary for me to take a pragmatic approach to conducting the interviews. This meant that some projects would schedule interviews with several staff on the same afternoon. Whilst this did not give me time to transcribe and analyse each interview before the next, I was able to note down the key themes presented in each interview and incorporate them into the following interview. I found this approach extremely valuable

as it allowed me to construct key themes quickly and efficiently while the data was still fresh in my mind, which in turn enabled me to delve deeper into the issues and themes presenting themselves almost immediately. The need to adopt this pragmatic approach occurred on three separate occasions within three different housing projects.

Prior to commencing the interview, I attempted to put the participant at ease by discussing general issues. In reality this did not seem to be particularly effective. At least four participants were nervous and two expressed their concern at how emotional they were already feeling about discussing their experiences. I attempted to put their minds at rest and took the opportunity to ask them how they would like me to respond to them should they become emotional during the interview. This allowed me to react in a way they preferred and also helped to limit my own feelings of helplessness when a participant became distressed. Several of the participants stated they did not want me to respond at all to any distressing displays and stated that I should just continue with the interview. Others requested I temporarily stop the interview until they indicated they were ready to continue again. Having had only limited experience of discussing emotive and sensitive issues with research participants in the past, I too felt quite anxious before the interview started. I ensured tissues and a glass of water were close at hand. I asked if I could record the interview and explained why I needed to do this. I revisited the information sheet, consent form and contact sheet. Three participants had not read the information provided and so I sat and waited for them to read through the documents. All participants had further questions

concerning the study and time was spent discussing the study and answering questions. After answering these questions, I was confident consent provided was informed. I reiterated that I may need to interview them again at a later date and ensured they agreed to this before I proceeded. I then asked for the signed consent form. In three cases, the consent forms had not been signed or signed by an independent witness. In these cases the participant had to leave the room to find an independent witness and returned with the signed and dated consent form.

Again, the welfare of the research participants was my paramount concern at all times during this study. If I became concerned the participant was becoming too distressed during the interview, I was prepared to stop the interview and reconvene at a later date and/or time or even abandon it all together. Due to the nature of the study I expected an emotional reaction. Interestingly, some participants commented on how they had found the opportunity to discuss their experiences and feelings during the interviews beneficial and cathartic. My study was always secondary to the participants' welfare.

For the first seven interviews I followed the first interview guide sheet (see appendix 2). This was informed by my preliminary literature review and advice from my supervision team. All questions were open and invited participants to describe their experiences and feelings concerning the study topic. I prompted new questions when the interview went off track or reached a point where no further comments were forthcoming. The

interviews lasted between 32 and 134 minutes. As data analysis was ongoing throughout the period of data collection, I developed a second interview guide sheet from interview eight to 12 (see appendix 2) incorporating the themes and issues arising in interviews one to seven. The final two interviews provided much the same information as those previously and no new data was presenting. This provided evidence that data saturation had been achieved.

Following my first interview, my data collection was guided by theoretical sampling (Charmaz 2010). Whilst there was limited choice of research participants, theoretical sampling helped to guide the relevance and selection of the subsequent participants and latterly helped to guide the questions I asked these participants. Interview questions asked were also informed by gaining theoretical sensitivity. Theoretical sensitivity is gained by accessing literature relevant to the themes and issues arising from the interviews (Charmaz 2010). Once no new data was presenting, I decided to stop collecting data as I felt I had reached data saturation. This was later confirmed when I completed my analysis and confirmed theoretical saturation in my data (Charmaz 2010). No further data collection was necessary. To be completely satisfied and to fulfil part of my original framework of evaluation criteria, (presented in the next section of this chapter), I presented a peer debrief report of my data collection and analysis to an independent peer de-briefer who confirmed in November 2012 that data saturation had been achieved. This peer de-brief report is available on the NVivo study file (available upon request).

As previously mentioned, as I approached the end of each interview, I informed participants the interview was coming to a close. For eight of the 14 participants, this statement seemed to reignite the interview and participants gave considerably more information at this stage. In some cases, they also took this opportunity to discuss their personal experiences of cancer. These discussions involved their individual, family and friendship group experiences. The interviews finished when participants had nothing further to add and I was satisfied they had regained their composure following any emotional distress. I offered participants the opportunity for a final contribution and thanked them for their input. The participants' welfare was paramount and I stressed the support on offer, encouraging them to refer to their contact sheet should they need to.

At the end of each interview I attempted to divert the conversation away from their experiences to more general topics such as gardening. This did not always work straight away and I found some participants returning to the interview topics and/or their feelings. This '*rebalancing*' sometimes took a considerable length of time. Whilst these interviews were at times emotionally draining for all concerned, I felt extremely grateful and privileged to have been part of them. Throughout the interview process it became clear the majority of staff participating in the study were struggling with feelings of bereavement and issues surrounding grief such as guilt.

Whilst some participants were openly emotional, others were not necessarily so, but were still clearly affected by their experiences. One interview

particularly stands out in my mind. It was the shortest of all the interviews with the participant providing short and concise answers. The participant displayed little or no emotion and laughed loudly at what seemed inappropriate times. Although I didn't show it at the time, I felt angry and frustrated at what I perceived to be a flippant and uncaring attitude. By adopting a reflexive approach and following discussion with my supervision team, I realised that this reaction may well have been their way of coping with difficult feelings and that on the contrary the participant may well have been deeply affected by their experiences but just simply had a different way of dealing with them.

Some of the accounts were quite shocking and at times and I found it difficult to measure my responses. For example I had not expected tenants' symptoms and physical deterioration to be so readily dismissed by primary healthcare services (see page 215). I found some of the interviews extremely emotional and I often needed several days gap between conducting the interview and transcribing it and again several more days between transcribing the interview and analysing it. This did become easier as the number of interviews I conducted increased. Upon reflection and as previously discussed whilst conducting some of the interviews closely together provided an in-depth picture of experiences instantly, it also limited my exposure to levels of emotional distress to an afternoon rather than two or three separate afternoons. Under the circumstances, this sometimes proved to be a welcome relief.

The emotional welfare debrief was useful and provided me with the opportunity to discuss any areas concerning my own emotional condition and with the exception of feeling what I have termed '*cancered out*', I coped well with the process. Being '*cancered out*' manifested itself in a variety of ways and led me to: -

- Regularly inspect my own body for unusual lumps, bumps and/or symptoms.
- Avoid discussing cancer outside of my work arena.
- Although never in the context of working with participants, I sometimes experienced a heightened level of insensitivity to the subject of cancer. (As a result of my exposure to cancer during this study, I became tactless and sometimes numb to the subject of cancer. For example I was asked by my supervision team to re-draft a presentation I had prepared of my study, as they felt elements of it could cause offence due to its potential insensitivity).

When providing my early transcripts to my supervision team for their review, my input at interview was commented on, and it was generally agreed that I needed to listen more and talk less. This constructive criticism was extremely helpful and through reflexivity I became more aware of my interview technique and how to improve upon it. I also became aware that to achieve a rapport with participants concerning sensitive and emotive topics, and by taking a symbolic interactionist approach, I could engage in a process

of research reciprocity where I shared my own experiences and emotions with participants (Harrison et al 2001).

2.3.5. Transcription

The interviews were transcribed in English, anonymised and transferred into the NVivo study file. Whilst some of the different regional accents were sometimes difficult to grasp, through the use of symbolic interactionism, I was not only able to gain a better understanding of the diction, slang and contextual meanings of participants' expressions but also the tacit meanings and values behind them. Where conversations veered off onto an unrelated personal experience, or where I offered unrelated discussion in an attempt to deepen rapport and/or engage in a process of reciprocity, I bracketed a brief explanation on the transcript of what was being discussed and then continued with the transcript *ad verbatim* when the relevant conversation reconvened or came to an end. I also adopted this approach on the transcript when the interview paused during times of emotional distress.

The transcription consisted of two stages. The first stage was creating a raw data transcript and the second stage was refining the data to make it readable and analysable. The second stage also provided a revision process ensuring accuracy and anonymity was assured. Firstly I listened to the interview, familiarising myself with the participant and their experiences, their accent and their personal expressions. Using a symbolic interactionist

approach I was able to gain a sense of the interview, alerting me to any cultural cues, the use of language and the tones used. I proceeded to transcribe at a slow speed, checking my understanding of the accents and my typing accuracy. Finally at the end of each raw data transcript I included the field notes I had taken immediately after the interview and later when I had arrived home. All interview audio files, transcriptions, and field notes are available on the NVivo study file.

Despite monitoring my accuracy in my raw data transcripts, some of the transcripts were still difficult to read and analyse and contained irrelevant material. Therefore, I carried out the following actions: -

- Edited the raw data transcripts ensuring no meaning or context was lost.
- In brackets gave a brief summary of the irrelevant topics being discussed at that time.

The transcription phase of the study was more challenging than I had initially expected for two reasons. Firstly, I am a proficient typist and did not expect the transcription to be so time consuming. Whilst I considered asking a third party to help with transcription, I realised that transcribing is itself an interpretative process and is therefore, the first step in analysing data (Bailey 2008). Secondly, I did not envisage my need to leave several days between

the interview and the transcription and then the transcription and the analysis phases.

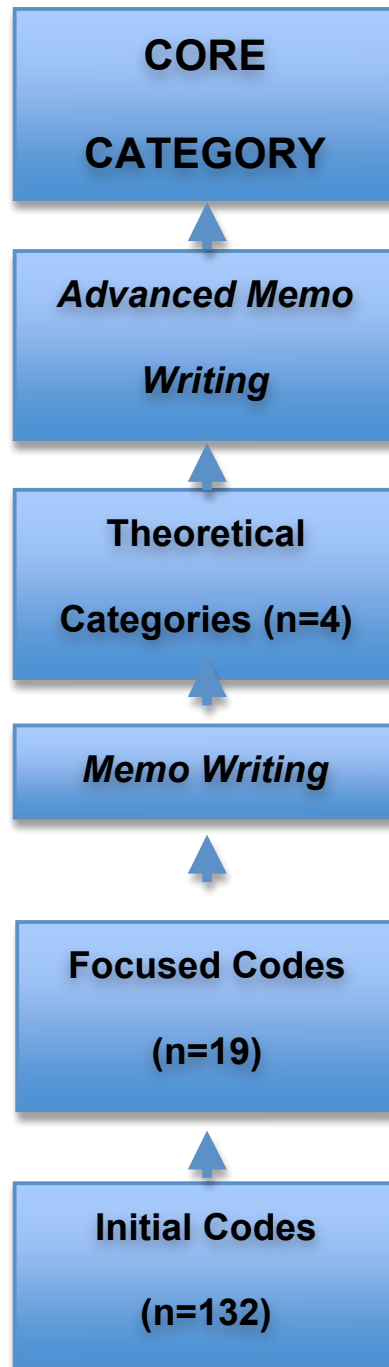
2.3.6. Data Analysis

Charmaz's (2010) version of constructivist grounded theory data analysis involves six stages: -

1. Constructing initial codes
2. Synthesising initial codes into focused codes
3. Writing of memos to raise focused codes
4. Conceptualising the focused codes into theoretical categories
5. Writing advanced memos exploring the relationship between the theoretical categories
6. Constructing a core category

Figure 2 gives a summary of the data analysis process starting from the creation of initial codes through to the development of the core category.

Figure 2 Summary of data analysis process



There are four phases of coding the data, initial coding, focused coding, creating theoretical categories and constructing a core category by using theoretical coding. The researcher moving quickly through the data word-

by-word, line-by-line or incident-by-incident and/or a mixture of all three, conducts initial coding. Initial codes should define what the researcher sees in the data, picking up general terms from an interview and representing the participant's meaning or action. They should be simple, short, precise and comparative (Charmaz 2010).

Focused coding is more conceptual allowing the researcher to synthesise larger segments of data. It can be more time-consuming as careful consideration has to be given to the categorisation of initial codes that make the most complete analytical sense of the data. From 132 initial codes, I developed a total of 19 focused codes. An example of how my initial codes became focused codes is presented in Box 2.

Box 2 Example of how initial codes are consolidated to form focused codes

INITIAL CODES	FOCUSED CODES
Anger, guilt, fear, frustration	Negative emotions
Satisfaction, pride, relief	Positive emotions

By concentrating on how the substantive codes relate to one another, the researcher is able to specify the possible relationships between categories (Glaser 1978). Gaining theoretical sensitivity simultaneously hones the direction of, and adds clarity to the conceptual analysis, ensuring the data fits and has relevance (Charmaz 2010).

Discovering the core category is perhaps the most challenging aspect of grounded theory and experiencing what has become known as a ‘*eureka*’ moment (Stern 2007) can be time consuming and demanding. The ‘*eureka*’ moment is when the core category is discovered. The core category should capture the heart of participants’ experiences and become the main research subject. The absence of a core category can make the researcher feel confused and lost. Once the core category has been discovered and the theoretical and conceptual analysis fits tightly and is relevant to the data, the process is complete. The emerging theory is grounded in the data.

Memo writing and advanced memo writing are fundamental to the process as it provides the researcher with an opportunity to unpick and explore codes and categories emerging from the data. By mapping ideas freely it not only encourages the researcher to stay close to the data but also allows them to explore more abstract ideas (Charmaz 2010). Using NVivo software, Version 9, my transcripts were coded line-by-line initially and then incident-by-incident to see if codes and incidents were comparable across transcripts. By doing this I was not only able to identify properties of my emerging concepts but was also able to ensure my analysis had fit and relevance (Charmaz 2010). By using both conceptual codes and *in vivo* codes, I remained open and close to the data, kept my codes short, simple and precise enabling me to compare and move quickly through the data. This was particularly important as I progressed through the transcripts. As the list of initial codes got larger, more time was needed to find the correct code, ensuring I did not duplicate codes. With this in mind, I reviewed all of the initial codes and their meanings and checked for any duplication regularly. Where duplicate initial codes were present I merged them into one.

The focused coding and development of the theoretical categories took longer. This was largely due to exploring the literature surrounding the codes (gaining theoretical sensitivity) and raising the conceptual analysis from description to a more abstract and theoretical level. One of my main challenges was discovering my core category and experiencing the long awaited and much anticipated '*eureka*' moment. For me the solution was to continue rigorously but patiently writing theoretical memos and undertaking

constant comparative analysis, visiting the data frequently but in between visits, allowing time to digest ideas. When the moment finally arrived, it was defining and memorable and it was definitely worth the wait, providing a thrilling start of the new phase of analysis as the theory started to emerge. The four phases of my coding, my memo writing and my conceptual maps are available on the NVivo study file.

2.4. Evaluation criteria within the qualitative paradigm

To ensure rigour within this study has been achieved, an original framework of evaluation criteria by which to assess the quality of this study has been developed. Initially this section will critically discuss the evaluation criteria developed for use with qualitative research. It will then examine the variety of evaluation criteria developed for grounded theory and constructivist grounded theory. Finally it will present an original framework of evaluation criteria developed for this study.

There has been considerable debate concerning the rigor and quality of studies employing qualitative methodologies such as ethnography, phenomenology and grounded theory and a requirement that the robustness of findings be effectively evaluated. As the quantitative epistemological perspective largely held prominence in scientific communities for many

years, it was initially assumed that the quantitative evaluation criteria of internal and external validity, reliability and generalisability were adequate tools to measure the rigor and quality of qualitative work. It has more recently been recognised that quantitative conceptualisations of validity and reliability are unsuitable for evaluation of qualitative research (Lincoln and Guba 1985, Hamersley 1992, Mays and Pope 2000, Horsburch 2003, Bitsch 2005). Due largely to the proliferation of qualitative methodologies, a requirement to develop different evaluative criteria based on disparate qualitative methods has arisen with some scholars (Glaser and Strauss 1967, Strauss and Corbin 1990, Cutcliffe 2001, Hall and Callery 2001, Whittemore et al 2001, Cohen et al 2007) concluding that adopting one generic evaluation criterion for qualitative work is ineffective and inappropriate. This realisation is perhaps a true reflection of post-modernist views. It recognises the presence of multiple realities and has consequently led to a plethora of criteria being developed for a plethora of diverse qualitative methodologies, with no consensus emerging and the possibility of reaching a consensus remaining fluid.

Devers (1999) asserts it is the criteria that provide the benchmark against which research can be evaluated and its value and worthiness calculated. Lincoln and Guba (1985) offer '*trustworthiness*' as an alternative finding of the research consisting of an assessment of credibility, transferability, dependability and confirmability. These assessments are considered as parallel constructs to internal validity, external validity, reliability and objectivity. Hammersley (1992) offers criteria that require studies to generate

substantive and formal theory; be empirically grounded and scientifically credible, aiming to ensure research has been produced in a rigorous and systematic way that is internally reflexive to limit bias. Inui and Frankel (1991) and Kuzel et al (1994) draw further on the work of Lincoln and Guba (1985) and Mays and Pope (1995) base their alternative criteria on the traditional, positivist philosophy.

The lack of consensus may be a reflection of the historical dominance of positivist methods and the view that research that does not measure up to quantitative evaluation criteria based on validity, reliability and generalisability is in some way less rigorous or of poorer quality (Lincoln and Guba 1985). It may also in part be due to the misconception that qualitative research is a unified field (Cohen et al 2007).

2.4.1. Grounded theory evaluation criteria

Scholars have put forward a variety of evaluation criteria for the different models of grounded theory. These include Slevin and Sines (2000), Lomborg and Kirkevold (2003), Chiovitti and Piran (2003), Elliott and Lazenbatt (2004). Whilst Charmaz (2010) has offered a set of flexible guidelines specifically for the evaluation of constructivist grounded theory research based around creditability, originality, resonance and usefulness, to date grounded theory evaluation criteria have largely been based on and/or

mirrored those developed by Glaser and Strauss (1967) and Strauss and Corbin (1990).

Grounded theory evaluation criteria developed by Glaser and Strauss (1967) relate to fit, work, relevance and modifiability. They state that it is crucial that data is not '*forced*' during the data collection and analysis process, allowing a core category to emerge which '*fits*'. For example, categories of theory must fit the data, the data must not be forced to fit the categories but confirmed by continual comparative analysis (Backman and Kynglas 1999). Glaser states that whilst the researcher should be encouraged to return to the field to gain further data with which to build the theory, the focus should be on the emerging theory rather than the actual data source (Glaser 1978). Relevance and work relate to the emerging core category. The core category must inter-link with the other concepts and their properties ensuring it theoretically integrates the emerging theory on all levels. The variation in the data must be accounted for by as few concepts as possible, maximising its parsimony and capacity (Glaser 1978, Hall and Callery 2001).

Glaser and Strauss' (1967) evaluation criteria have been criticised for their assumption that a natural world is being observed and analysed (Blumer 1969), and as such, it is unrealistic to assume that the researcher can operate objectively within this context (Hammersley 1987, Popay et al 1998). Both in Glaser and Strauss' (1967) evaluation criteria and also to some extent in Strauss and Corbin's (1990) evaluation criteria there is little or no recognition of the relationship between the researcher and the participant.

This lack of recognition of relationship has implications when examining the power and trust relationships between researcher and participant (Hall and Callery 2001). According to Lincoln (1995), power and trust relationships between researcher and participant are addressed through relationality, contributing to ethical standards as well as standards of quality *per se* (Lincoln 1995).

Strauss and Corbin's (1990) grounded theory evaluation criteria consist of two sets of criteria, namely the adequacy of the '*research process*' (research should be evaluated by the very constructs that were used to generate it) and the empirical grounding of the '*research findings*' (the overall product of the research) (Hall and Callery 2001, Elliott and Lazenbatt 2004).

They suggest that assessment of the adequacy of the research process should be based on seven criteria and the research product based on a further seven criteria. The first seven criteria relate to sample selection, emergent categories, events and incidents that indicated these categories, the process of theoretical sampling, emergent hypotheses, discrepancies surrounding these hypotheses and the basis of the selection of the core category. They state that if the research provides this vital information, it will enable readers to explore and investigate the appropriateness of the complex coding procedure (Strauss and Corbin 1990).

The seven criteria surrounding the research product are based on generated concepts, systematic relation to the concepts, conceptual link to categories, levels of variation in the emerging theory, the inclusion of both the micro and macro sources, accommodated flexibility for change within the study and the significance of the findings (Strauss and Corbin 1990).

The approach taken by Strauss and Corbin (1990) has been challenged by Miller and Fredericks (1999), who claim these criteria are problematic and could result in the evaluation becoming a circular issue (Elliott and Lazenbatt 2004). Whilst it is not clear why Miller and Fredericks (1999) consider this circular issue to be problematic (Elliott and Lazenbatt 2004), on closer inspection of their challenge, it is clear they base their critique on Rudner's (1966) logical positivist philosophy of science approach (also known as neo-positivism). Logical positivism imposes an inappropriate simplification on the social sciences when examining empirical evaluation of social science hypotheses. It presupposes the comprehensive generality of the hypothetico-deductive model of confirmation theory, which is derived from the assumption that the logic of scientific reasoning, must be the same in every area of science (Kinkaid 1996). For example, Rudner (1966) states,

'The logic of justification (the logic of validation as he also refers to it), consists of a proper application of scientific standards to make judgments about a claim (e.g. theory, hypothesis, event, and so forth)' (Rudner 1966, p.72).

As Strauss and Corbin's (1990) model of grounded theory is based firmly in the post-positivist paradigm and grounded theories are inductive and based within a symbolic interactionist ontology, this challenge from Miller and Fredericks (1999) (which is also reiterated in the work of Elliott and Lazenbatt (2004)) seems neither relevant or appropriate when discussing the development of evaluation criteria for grounded theory research.

2.4.2. Establishing constructivist grounded theory evaluation criteria

In keeping with the principles of constructivist methodology, as previously stated, Charmaz (2010) offers a set of flexible guidelines for evaluating constructivist grounded theory based on credibility, originality, resonance and usefulness, and states that the research audience should be considered when establishing criteria, as they will ultimately judge the quality and usefulness of the final product. In contrast to the Glaser and Strauss (1967) evaluation criteria of fit, work, relevance and modifiability and Strauss and Corbin's (1990) evaluation criteria of process and product, it denies the existence of an objective reality and recognises and incorporates the mutuality between researcher and participant by addressing balances of power and trust relations, positioning the researcher as co-producer throughout the research process.

Strauss and Corbin's (1990) grounded theory evaluation criteria of '*research process*' and '*research findings*' provide a detailed account of the procedures, canons and evaluative criteria specific to their model of grounded theory. This enables critics to accurately judge how the researcher carried out the procedural operations and analysis within the research process and when investigating the empirical grounding of findings (Strauss and Corbin 1990). However, Strauss and Corbin (1990) do not provide a prescription or guidelines on how the researcher should provide this information. Nor do they provide a criterion for evaluating the study's originality or usefulness.

After careful consideration of the variety of evaluation criteria for grounded theory studies available, I decided there was not one formalised framework that could meet this study's requirements. Consequently I decided to develop an original framework of evaluation criteria, based around the transparency and auditability of the research process and product and the originality and usefulness of the research product.

This framework is largely based on a combination of both Strauss and Corbin's (1990) and Charmaz's (2010) approaches for evaluating grounded theory research. Furthermore, whilst the academic community are well versed in both Strauss and Corbin's (1990) and Charmaz's (2010) approaches, the originality of this specific framework of evaluation criteria, is founded on its combination of Strauss and Corbin's (1990) and Charmaz's (2010) work and their subsequent application. According to Cryer (2000) if

existing techniques, tools and procedures are used in new and untested ways, this justifies a claim of originality.

Box 3 Original Framework of Evaluation Criteria

EVALUATION CRITERIA	METHOD
Research Process	Transparency and auditability of the research process
Research Product	Transparency and auditability of the originality and usefulness of the research product

Box 3 above provides the formalised framework for evaluating this study. It is based on transparency and auditability of the research process and product, and the originality and usefulness of the research product (see appendix 8 for the tools used to achieve these).

As the second part of the framework of evaluation criteria is based on the research product, Charmaz's (2010) guidelines on the originality and usefulness of the research product are outlined below. With regard to the study's originality, Charmaz (2010, p. 182) asks the following series of questions of the research: -

- Are the categories fresh and offer new insights?
- Does the analysis provide original conceptual rendering of the data?
- What is the social and theoretical significance of this work?
- How does the grounded theory challenge, extend, or refine current ideas, concepts and practices?

Originality of this study will be identified, discussed and presented through the preliminary findings, discussion and conclusion sections of this thesis. With regard to the study's usefulness, Charmaz (2010, p. 183) asks the following series of questions of the research: -

- Does the analysis offer interpretations that people can use in their everyday worlds?
- Do the analytic categories suggest any generic processes?
- If so, have these generic processes been examined for tacit implications?
- Can the analysis spark further research in other substantive areas?
- How does your work contribute to knowledge and the making of a better world?

This study's usefulness will be identified, discussed and presented in the conclusion of this thesis and through the dissemination of the findings of the study. The dissemination of the findings may help to develop policy, educational training and practice in the research area.

Finally this study was peer debriefed and audited. The peer debrief took place once the data collection and analysis had been completed by an external peer debriefer. The purpose of this peer debrief was to review the data analysis and offer any additional perspectives for data analysis and suggest any further avenues to investigate. A peer debrief summary report was provided by the researcher to the peer debriefer and a meeting between

the peer debriefer and researcher took place to discuss the peer debriefs' findings (see page 121 and appendix 8 for further information).

Upon completion of this study an external inquiry audit took place by a fellow PhD student on the NVivo study file before submission to ensure the researcher had met accepted academic standards. The auditor was provided with a complete copy of the NVivo study file on a USB memory stick. They were also provided with an inquiry audit table to complete. This table asked the reviewer a series of questions relating to their experiences of accessing and reviewing the study file through NVivo (see appendix 8). Both the peer debrief summary report and the completed inquiry audit table are available on the NVivo study file.

2.5. Summary

This chapter has discussed the origins and foundations of social science, its epistemologies and its ontology and presented different perspectives of research based within both the quantitative and qualitative paradigms. This included issues relating to the epistemological dominance of positivism and was followed by a discussion on the variety of different methodologies available. A detailed exploration of grounded theory has been presented with further discussion concerning the different approaches on offer. An exploration of constructivist grounded theory and a rationale for its use in this study followed. This study's research design was then considered and the methods used to conduct it were reviewed including the processes of, and issues relating to, sampling and recruitment within the participating service organisations. The ethical considerations of conducting research around cancer and the sometimes sensitive and emotive nature of conducting the fieldwork have also been considered. In the final section, research evaluation criteria were explored in depth and an original framework of evaluation criteria for use in this study was presented based on the research process, and the originality and usefulness of the research product.

Having set out the methodology, research design and evaluation of this study in this chapter, the findings will be explored in subsequent chapters, with some preliminary discussion. These are organised in relation to the four theoretical categories and the core category.

Table 4 Study categories

THEORETICAL CATEGORY	CORE CATEGORY
Role Identity (How staff see their role)	BUILDING RESILIENCE
Role Ambiguity (How supporting a tenant with cancer changes their role)	
Role Emotions (How staff feel about these changes)	
Role Resolution (How staff try to cope, resolve and prepare for these changes).	

Table 4 above highlights the four theoretical categories and core category that emerged from the data. These categories are based on the researcher's interpretation of the data. Whilst they are presented separately here they impact, relate to, and sometimes overlap with each other and this is reflected in Chapter 8 where these relationships are explored.

CHAPTER 3

Role Identity

Building on the introduction of the theoretical categories at the end of the previous chapter, this chapter will critically discuss the study's findings in relation to the theoretical category of role identity. This category relates to how staff perceive and identify with their work role and the value they place on aspects of this role. Whilst some of these values are outlined and supervised by the service organisation employing them, others may be subjective and based on their team and individual values, expectations and practice.

None of the staff participating in this study (see table 3, page 108) had formal healthcare training and six had no prior experience of working in a healthcare setting and had not previously supported a tenant with a serious illness and/or through death. Given the staff backgrounds and experience, being required to support a tenant with a serious illness such as cancer may challenge their role identity, blurring the boundaries of their existing role identity. For example, staff may be expected to provide the tenant with a bed bath. They may have no experience of providing a bed bath and may not see this activity as part of their usual role. Retaining confidentiality,

prioritising their workloads and the emotional dimension of the long-standing relationships they share with the tenants also creates tensions and dilemmas, potentially upsetting the '*status quo*' when the tenant becomes ill.

The theoretical category relating to role identity consists of six focused codes and 20 initial codes (see table 5 overleaf). The following section will discuss and explore each of the six focused codes by sub-heading and their respective initial codes, which are highlighted in bold and italics within the text of this chapter.

Table 5 Theoretical category and focused codes relating to role identity

THEORETICAL CATEGORY	FOCUSED CODE
Role Identity	Staff profile
	Staff know best
	Staff commitment
	Special relationship
	Being strong
	Being professional

3.1. Staff Profile

There is no clear definition of what constitutes a support worker or why people become support workers in the first place (Manthorpe and Martineau 2008). In a scoping review carried out by Manthorpe and Martineau (2008) on behalf of the Social Care Workforce Research Unit, Kings College London, it is argued that one of the reasons for the lack of clarity surrounding this role may be that the term ‘*support worker*’ describes a variety of similar roles such as social care worker, community support worker, home care worker, mental health support worker, social work assistant and personal assistant. They further suggest the role of a support worker means

supporting a service user or supporting a professional or both, lacks professional accreditation, receives low pay, and has variable access to training. Support worker tasks sometimes overlap with those of their professional colleagues (Manthorpe and Martineau 2008).

As previously stated on page 70, within social care settings, the support worker role aims to facilitate independence, choice and autonomy (Manthorpe and Martineau 2008, Windley and Chapman 2010, Todd 2013). It is recognised that the relationship boundary between support worker and service user is often blurred between employee and friend and this may leave support workers vulnerable to exploitation by the service organisation where support staff feel obliged to work longer hours than they have agreed or receive pay for (Flynn 2005).

In this study, participants discussed aspects of their role identities they valued. These valued characteristics included demonstrable commitment to the tenant, experience of working as social care workers, professionalism, being emotionally strong, having a positive outlook and not complaining. How participant's colleagues' perceived their performance also appeared to be important. Participants believed staff needed these attributes to be '*good*' at their job and those who demonstrated these were perceived to be the most valuable and gained the most respect from their colleagues. These characteristics became particularly important when the tenant became ill, as staff considered the more experienced and more committed staff were, the

stronger and more able they were to cope with the new challenges they faced.

Participants revealed that older staff with greater experience and longer ***length of service*** were considered by the staff team as being crucial to the team and the most capable at their jobs as Anna explained: -

I thought to myself the other staff they wouldn't have been any good because they were really young. That sounds awful but they hadn't been in the job long (Anna, senior support worker to Jim).

Dodevska and Vassos (2013) report having a long employment record, being physically well presented and arriving to work on time were valued attributes of support staff back in the 1950s and 1960s. More recently the service users' voice of what constitutes an effective support worker has been reported in the literature (Dodevska and Vassos 2013) and studies (Hatton et al 2009, Clarkson et al 2009) report that being calm, caring, honest, kind, understanding, willing to help and providing a sense of protection are desirable interpersonal qualities for social care workers. Managers from service organisations placed greater emphasis on practical skills and knowledge (Dodevska and Vassos 2013). From the perspective of tenants with learning disabilities, an Australian study conducted by Further Inclusive Learning and Development (FIELD) (2006) reported compassion, empathy, respect for tenants, being friendly, polite, honest and trustworthy, having a

positive attitude towards tenants and treating them with dignity, being practical and efficient workers were consistently mentioned. Both Clarkson et al (2009) and Hatton et al (2009) report similar findings to FIELD (2006), with the study by Hatton et al (2009) investigating both the tenants and professionals' views. Interestingly in Hatton et al's (2009) study, tenants with learning disabilities emphasised the importance of personal and interpersonal staff characteristics whereas the professionals placed more emphasis on practical and knowledge work skills. Clearly, these differing perceptions add to the lack of clarity and consistency surrounding the effective carer role. Perhaps as staff gain experience in their roles and become older in the process, their interpersonal and practical skills and knowledge increase. This process of achieving role adeptness may help to explain why older staff with more experience are sometimes perceived as being the most valuable and the most capable at their jobs.

May, a participant in this study, has been employed as a social care worker for over 25 years and has known Joyce, the tenant with cancer, during this time. For the majority of this time, May has been involved in Joyce's care. When asked about the general profile of the staff supporting Joyce she was proud to share her background: -

Well I am a key worker. Like I've been doing it 28 years but one of her (Joyce's) key workers has been there 14 years working alongside me (May, social care worker to Joyce).

Later in the interview I asked May how she was coping with Joyce's condition, particularly as she had known her for so many years. May claimed her ability to cope was largely down to her level of experience both in the job and her experiences of cancer outside of her job with her own family: -

I don't know really. I think a lot of it is experience. Because I know some of the girls couldn't cope as well as I did and I think with all the years of experience and I have seen like my dad died of cancer. I have had a few others over here, I've nursed them with cancer and I've had a lot of people. I mean like all the years I've been here and I find that that is my, I'm special at that when people are ill and dying (May, social care worker to Joyce).

Anna, working in another project and employed by Sterling for over ten years, felt that if she had not been persistent with healthcare staff concerning the symptoms of Jim's illness, he may never have been officially diagnosed with cancer. Anna's concerns are echoed in the existing literature, which reports a diagnosis is largely dependent on someone other than the patient noticing something is wrong and that social care workers have a significant influence on treatment decisions (Langan et al 1994, Tuffrey-Wijne et al 2009, Ferguson et al 2010). Anna argued that her ability to be persistent was the result of her age, experience and the length of time she had been in the job. Similarly, Janet, Anna's senior manager echoed this view when asked whether the staff relationships she shared, had helped her to cope.

Janet claimed the two members of staff that had been of most help were the two older and most experienced staff:-

Yes. Especially with Anna and Richard. Not so much the others in the team because of lot of them were young and they didn't know what was going on and they had no experience. They hadn't even any experience of anyone dying (Janet, manager to the team supporting Jim).

Janet's comments indicate that staff that had greater life experience and greater experience within their roles were most valued.

Twelve of the participants interviewed in this study had worked in support and/or care settings for some time (>10 years). This length of service meant at least nine of the study participants had experience of working within institutional settings. This sometimes shaped the way they provided support and impacted on their role identities.

As previously discussed on page 39 prior to deinstitutionalisation, the majority of people with learning disabilities lived in the community, and some were supported in large institutions based on the medical model. Many staff who had previously worked within institutional settings viewed the ***institutional days*** negatively and were pleased these days were over. This sometimes shaped their values and how they perceived and performed their current staff roles. For example, Kelly, a key worker to Joyce, had over 15

years experience of social care working and was keen to ensure the support she provided to Joyce did not echo the philosophies surrounding the medical model of care adopted in institutional settings. Prior to working for Sterling, Kelly was employed as a support worker in a long-stay hospital for people with learning disabilities. Whilst not all staff viewed their institutional experiences negatively, Kelly was adamant her own experiences of supporting a tenant through illness whilst working in an institution, would not be repeated. She argued the support she provided Joyce during her illness would be completely different:-

I didn't want the staff to have ownership of it (Joyce's cancer), because in institutionalised days that's how they used to be. I mean I saw some horrendous things when people were dying and the way people behaved. They would stand in the room and talk about them and say 'oh she ain't got long now'. I will never forget that, I will never forget that in all my years but those things really shaped the way I was able to witness things and think that is horrendous and not going to be something I am part of (Kelly, key worker to Joyce).

Clearly for Kelly, her experiences of working in an institution had a profound effect on how she perceived her role identity and the staff role she adopted now: -

I would also say be true to yourself. Well if I hadn't have tried to break away from an institutionalised way it would be happening here now, little institutionalised ways that you have to keep saying to people well that's why we are doing it this way because it's not my place to say that someone can only have tomatoes on toast three times per week because it's good for them. I can advise them but they can choose. So you would have to be true to yourself because you have to bring a bit of you to the mix as well (Kelly, key worker to Joyce).

Another staff member, Rachel, claimed the closure of the institutions had created a vacuum for tenants who became ill. Rachel argued that at the time of deinstitutionalisation no forward planning had been given to the future of ageing tenants requiring medical care in the community. She commented on how this lack of forward planning is increasingly creating challenges for staff and service organisations: -

I think what's happened as well is that you have probably come at a time where all the old institutions were resettled back 1970s onwards and all the big ones in this area were 2001, 2002 were all the last people from the local institutions, I mean they are all getting older now. So now you are going find right that is when they are going to need all this medical care. If something goes wrong, one of the biggest issues is medical care I will be honest with you. Not just cancer but any kind of medical care even dental care. I have got another service user at the moment that needs a full extraction and he is a particularly challenging service user but to get this

service user into a hospital to get his teeth out has taken a huge strategy plan and this is the thing now. These times are coming now and there are so many issues. It probably should have been thought of when people were resettled (Rachel, manager to the team supporting Neil).

Rachel clearly perceives accessing mainstream health services for the tenants as problematic and there is a wealth of literature corroborating her concerns (Mencap 2004, 2007, Backer et al 2009, Emerson and Baines 2010, Emerson et al 2012, Heslop et al 2013).

One participant expressed regret at the closure of long stay hospitals providing institutional care not least because she claimed healthcare was facilitated more readily. This participant commented on how staff behaviour was more closely monitored within an institutional setting with there being less of an opportunity for staff to abuse tenants compared to living in residential settings where she believed staff were largely left to their own devices. She also commented on how staff roles were clearly defined within the institutional setting and staff and tenants alike knew what was expected of them. In contrast, a recent study exploring staff reflections on the change from working within institutional settings to community settings, staff reported they felt under greater scrutiny by their managers who watched them more closely whilst working in a community setting. This study also reported that staff were more relaxed working in community settings and were able to spend more time with tenants, offering them more choice (Salmon et al 2013). Whilst the sample involved in this study was small and cannot

therefore be representative of the wider population, it does still contribute to the development of understanding surrounding staffs' reflections of institutional and community settings.

This study also revealed a ***gender dimension to caring***. From the recruitment phase of this research it was evident that the majority of participants were female and of these seven were mothers. Female participants reported their gender naturally equipped them to provide support to their tenants. They argued by being female, they had the advantage of being able to instinctively adopt a maternal approach. For example, Rachel claimed women were more empathetic and caring and had a natural maternal instinct:-

I think women are a bit more empathetic. I don't know but I think we have got that caring, motherly thing that we use don't we? (Rachel, manager to the team supporting Neil).

Perhaps a maternal approach is not always what people with learning disabilities may want and/or need and appears contradictory to service philosophy, which aims to promote autonomy and facilitate independence. Clearly there is tension between the two conflicting duties of protecting tenants from risk and promoting their independence. In an ethnographic study involving over 450 hours of observation over a ten month period carried out by Hawkins et al (2011) focusing on a residential setting involving

tenants with Prader-Willi syndrome, they suggest that some support workers digressed from standardised risk management procedures to facilitate tenant independence. Another participant commented on how one female staff member could be abrupt with tenants and colleagues but quickly blamed this on having previously worked with men where she had had to stand up for herself.

This gender imbalance within service organisations providing support to people with learning disabilities correlates with the wider literature. The gendered dimension of both nursing and caring work is not a new phenomenon (Poole 1997, Kirkman 2001, McLean 2003, Gray 2010, Kirkman 2011, Perz et al 2011). Historically, caring work has been '*women's work*' (Kirkman 2005, Poole 1997) and is generally not highly valued (Waring 1988). Women's traditional caring roles within the family and perceptions of their natural nurturing ability have ensured that the majority of care work has fallen to them (Twigg 2006). Women constitute the majority of workers in the caring sector with only 14 per cent of the UK social services workforce being men (McLean 2003). Within the formal sector, Kirkman (2011) suggests nursing has been predominantly responsible for the professionalisation of care that has included duties that mirror unpaid work women do within the home, such as supporting daily activities including eating, sleeping and hygiene. Kirkman (2011) argues this increasing emphasis on social care work, has resulted in professional care work once again becoming deskilled with untrained workers gradually taking over paid care work. This deskilling process has continued since the 1990s with

increasingly technical '*bodily*' care (Twigg 2000) such as wound care, hygiene and administering medication being undertaken by staff without professional accreditation rather than nurses. This has further blurred the boundaries between paid and unpaid work. These traditional attitudes and circumstances have resulted in more women than men taking up care work and may contribute to some of the sexist attitudes surrounding this work.

As this study sample was relatively small, the one male participant was not asked to comment on his experiences of being a male social care worker. The researcher felt that to single this participant out may have been perceived as unfair and/or discriminative. Whilst there is a lack of empirical research exploring men's attitudes in this regard, expectations of masculinity within society appear to perceive men who take on caring roles as not being '*real*' men (Women's Commission 2005). A recent study exploring men as a minority employed in statutory social care work (McLean 2003) suggests on the one hand female workers welcome male involvement in the workplace because their presence may enhance pay and occupational status (Williams 1995) but are often concerned that men may receive special treatment because they are in a minority. Men themselves often feel isolated and lack male companionship within a social care setting but also feel they bring fresh perspectives to a predominantly female working environment (McLean 2003). In view of the ageing population and the greater demand on the need for social care, more research needs to be carried out exploring the gender imbalance within care work with a view to increasing the potential pool of male care workers. Perhaps by placing the quality of care provided at the

heart of the debate, rather than issues relating to traditional, socially constructed perspectives of gender, understandings of service users needs and the overall quality of care provided could be greatly enhanced.

3.2. Staff know best

The majority of participants (n=13) had extensive experience and knowledge of the tenants' capabilities and needs having supported them for some time (>5 years). (See table 3 on page 108). This gave staff a sense of responsibility, making them feel valued employees and in turn increased their sense of importance and self worth, providing them with a higher status within the team. It also allowed some staff to position themselves as gatekeeper to the tenant. **Gate keeping** is a term used to describe a person(s) controlling access to something or someone, usually a vulnerable person. By adopting the role of gatekeeper, staff were able to control others' access to the tenant. Whilst at times this paternalistic attitude may have been justified (see page 157 for further discussion on the tensions between providing protection from risk and autonomy), this also reinforced their role identity of being responsible and committed to the tenant and valued within the wider team. Of the six tenants with cancer discussed in this study, three had staff supporting them who engaged in gate keeping behaviour.

Several of the staff interviewed were 'key workers'. This system allocates a staff member or 'key worker' to a tenant. The key worker is responsible and accountable for the care of that tenant when they are on duty. Key workers also support tenants to make decisions. At times this role enabled the staff member to act as gatekeeper. This imbalance of power sometimes created tension and conflict amongst other staff. Similar reactions are evidenced in the literature. Deeley (2002) reports that despite service provision adopting the principle of normalisation as the ideology for providing support to people with learning disabilities and for promoting freedom of choice and autonomy, there remains a minority of staff who continue to adopt a paternalistic approach towards the tenants they support which can cause tension and conflict (Deeley 2002). For example, key workers supporting Joyce decided when and how the rest of the team supporting her would be informed of her diagnosis. Some staff claimed this left them feeling excluded from Joyce's care and unable to provide her with the support she needed in coming to terms with her diagnosis. May explains below the impact of this exclusion: -

Joyce had been sobbing all night and the night staff went in there and she was breaking her heart and they were fuming the night staff were. They said 'we did not know and we couldn't provide Joyce with the support and care that she needed', and do you know, it broke my heart (May, support worker to Joyce).

Both practice and policy directives have endeavoured to move away from the paternalistic approach of providing social care support by promoting choice

and autonomy through person-centred planning, direct payments and individual budgets (Department of Health 2005, 2006, 2008a, 2008b, Prime Ministers Strategy Unit 2005, Social Exclusion Unit 2005, Welsh Government 2011). In practice, barriers remain for social care workers who encounter philosophical, social and practical dilemmas whilst supporting tenants on a daily basis (Harris 2003, Finlay et al 2008, Windley and Chapman 2010). For example, service inspection regimes and healthcare and risk assessments are sometimes contrary to promoting choice and autonomy. It could also be argued that service organisations themselves help to foster a paternalistic culture (Hawkins et al 2011). By service organisations acting in the tenant's best interests, this action sometimes takes precedent over the tenant's personal wishes (Finlay et al 2008) leaving social care workers to navigate these dilemmas.

From a total of 14 participants, 13 stated they had '*inside knowledge*' and knew there was something wrong with their tenant prior to a hospital referral and/or diagnosis. For example, Anna who had supported Jim for many years claimed to have known something was wrong for a considerable length of time: -

I had my suspicions for months and months and months but we were pushing the doctors, the GP, and we were just pushed aside all the time
(Anna, senior social care worker supporting Jim).

These findings are consistent with other studies that report on obtaining an untimely cancer diagnosis and how this results in the patient's treatment options being severely restricted (Hogg and Tuffrey-Wijne 2008, Tuffrey-Wijne et al 2009). They are also consistent with other findings that report on how social care workers' concerns or '*inside knowledge*' surrounding the tenants deteriorating health status are dismissed or largely ignored by primary healthcare professionals (Baxter and Bradley 2008, Hogg and Tuffrey-Wijne 2008, Creswell and Tuffrey-Wijne 2008, McIlfatrick et al 2011, Wyatt and Talbot 2012, Heslop et al 2013).

Many staff described their inside knowledge as a '*gut feeling*' or a feeling they had '*deep down*'. These statements relate to staff claiming they had intuitive feelings concerning the tenant's condition. Linking the wider nursing literature, the definition of intuition is unclear, although it is accepted that intuition positively affects the quality of patient outcomes (McCutcheon and Pincombe 2001). Agan (1987) suggests it is a dimension of '*personal knowing*', one of the four patterns of knowledge identified by Carper (1978) with the other three being empirics, (the science of nursing), aesthetics, (the art of nursing) and ethics, (the component of moral knowledge in nursing). Intuition is not some mystical occurrence that just occurs, but is a combination of attributes such as experience, knowledge personality and environment (McCutcheon and Pincombe 2001). Within this study, the reliability of intuition depends on the staff member's past knowledge and experience of the tenant. By claiming to have this type of intuition, staff are

exhibiting their knowledge and experience of the tenant thereby reinforcing desirable and valued characteristics of their role identity.

Betty argued the entire team knew there was something wrong with Joan and that if the staff had not had the depth of knowledge concerning Joan, then her experiences may have been worse in some way:-

We just knew it was something seriously wrong. But I think deep down we all knew there was something you know. They knew this lady so, so well and could identify lots of things and ... and it's just thinking well if it wasn't for them. If it had been lots of strangers, that wouldn't have happened would it? (Betty, manager to the team supporting Joan).

3.3. Staff commitment

Staff displaying commitment to their job and their tenant demonstrated a vital component of their role identity. This was particularly important when a tenant became ill. By taking on new challenges to meet the changing needs of the sick tenant, the boundaries of the staff role identity became unclear. This lack of clarity sometimes caused role ambiguity (see chapter 4, page 199). In an attempt to meet these changing needs, staff constantly displayed their commitment to the tenant by working extra hours, sometimes unpaid, to ensure the tenant had continuity of care. Other ways staff

demonstrated their commitment included thinking up imaginative ways of making the tenant as comfortable as possible, persevering regardless of the challenges before them and providing support above the expectations of their usual roles.

Regardless of the staffing levels, participants described how they continually supported tenants. Staff demonstrated this level of commitment to ***time management*** particularly when the tenant was ill.

In all cases, staff reported they had worked longer hours than their shifts required and in the majority of cases worked extra hours unpaid to make sure the same staff constantly supported the tenant regardless of the problems they may have had with staffing levels. Betty highlighted this when she explained:-

I had two staff on maternity leave and I had one staff on long term sick and we had no staff, but we covered every hour, because that staff team would not leave her (Betty, manager of the team supporting Joan).

Some participants reported they were encouraged to claim back the extra time they had worked as time owing. Betty's comments demonstrate how committed the staff were in providing the support the tenant required. In both Fisher and Byrne's (2012) and Bradshaw and Goldbart's (2013) studies positive relationships with tenants with learning disabilities were fundamental

to good practice. The wider literature reports the quality of work support staff provide, ultimately reflects the quality of support tenants receive (Emerson et al 1999, Felce and Emerson 2001, Robertson et al 2005, Mansell and Beadle-Brown 2012). To maintain quality service provision, support staff should have positive relationships with the tenants they support, be content in their role and be adequately supported (Thomas and Rose 2009).

Whilst the commitment many social care workers demonstrate is admirable, it is recognised that support staff working longer hours than their designated shifts, sometimes unpaid, can lead to increased levels of work stress. Findings from Folkman et al (1987) report work stress occurs when the demands of a role exceed the internal and external resources to fulfil the role. This stress alongside the low job status, low pay, low staffing levels, poor access to appropriate training and heavy workloads, contributes to one third of paid social care staff supporting people with learning disabilities experiencing a mental health problem (Hatton et al 1999). A portion of these will experience burnout (Hastings et al 2004, Devereux et al 2009, Mutkins et al 2011, Ryan et al 2011). Several participants within this study discussed how they experienced stress (see chapter 5, page 273 on role emotions). Ekstedt and Fagerberg (2005) describe burnout as the emotional state staff find themselves in when they deploy unsuccessful coping strategies when under long term work stress. Burnout is three dimensional, and includes emotional exhaustion, depersonalisation, and a lack of personal accomplishment (Maslach et al 1996). Whilst burnout occurs in a variety of workplace settings, it is especially common in human service personnel,

particularly those who give more of themselves emotionally than they receive (Maslach et al 2001, Hastings et al 2004). The psychological impact and levels of stress experienced by social care workers supporting a tenant with cancer are unknown. Findings from this study suggest participants experienced stress as a direct result of the role ambiguity they encountered whilst supporting a tenant with cancer (see chapter 4, page 199 on role ambiguity). Role ambiguity creates work stress (Furniss et al 2012, Herber and Johnston 2012) and work stress is linked to an increased risk of burnout (Ryan et al 2011). Although at the time of writing, none of the participants in this study appeared to be suffering from burnout.

Interestingly, relationships between social care workers and tenants based on reciprocity can help to alleviate burnout (Thomas and Rose 2009). Based on Macintyre's (2007) model of internal goods, (practices developed by enhancing existing expertise), professional commitment provides mutually beneficial emotional fulfilment both for the social care worker and the tenant. For example, Theodosius (2006) suggests giving sympathy usually results in receiving gratitude and this process of mutual fulfilment demonstrates a genuine emotion emerging from the interaction itself rather than a conventional and/or expected emotional display such as those emotional displays associated with surface and deep acting (Hochschild 1983). Perhaps this exchange resulting in mutual benefit indicates why some support staff are keen to demonstrate their commitment to their tenant.

The ways in which participants demonstrated their commitment to their tenants sometimes involved persevering with healthcare staff. There was a general consensus amongst participants that **perseverance** and refusing to take no for an answer was an important aspect of getting the healthcare staff to listen to their concerns regarding the tenant's illness. They argued they were justified in persevering to the point of annoying the primary healthcare staff, in trying to get their concerns taken seriously and acted upon. These findings echo those reported by Mencap in '*Treat Me Right*' (2004). In this study the tenants did not have a mother able to negotiate their care path. It became the responsibility of their support staff to take up this pivotal, but arguably, paternalistic role.

Anna made frequent visits to Jim's GP, insisting something was wrong with him and requesting they investigate her concerns. These concerns were ignored and it was not until Jim's speech and language therapist expressed her shock at his visible deterioration to the primary healthcare staff, that something was finally done. These findings suggest Anna's concerns were only taken seriously because a qualified speech and language therapist relayed them. Perhaps the speech and language therapist was perceived by primary healthcare staff as having a higher occupational status than a social care worker and therefore, in the eyes of the primary healthcare staff, may have had greater credibility. Whilst there is lack of literature investigating healthcare staff perceptions of social care staff, the recent Confidential Inquiry into the Premature Deaths of People with Learning Disabilities (CIPOLD) (Heslop et al 2013) identified similar worries from the family, the

person with learning disabilities and/or the paid social care worker whose concerns were not taken seriously by healthcare staff and as a result, encountered problems and delays in obtaining a diagnosis. The study conducted by Heslop et al (2013) was tasked with investigating the avoidable or premature deaths of people with learning disabilities through retrospective reviews of deaths over a two-year period across South West England. Evidence exploring the power differential within healthcare settings between social care staff and healthcare staff also exists. The latter is seen to wield more power than the former (Grabb 1997). A study carried out by Rutman (1996) suggests that a lack of recognition and respect for support workers knowledge and skills is one cause of this perceived powerlessness. Another study carried out by Wild et al (2010) explored how social care staff working in residential homes perceived their own status. They reported that whilst social care staff considered themselves to act professionally within residential settings, they were unsure how their status was viewed in a wider healthcare setting. It could be argued that support staff lack the confidence, support and technical ability to communicate effectively with healthcare staff.

When Anna was asked what advice she might give to a colleague when primary healthcare staff dismissed concerns of a tenant's deteriorating health, she stated:-

Keep on and on and on. Just don't give up pushing. Don't give up and don't think you are annoying the doctors. Just keep going and going and

going. I would just keep on and on. I wouldn't give up. Don't give up, keep going and just keep going (Anna, senior support worker to Jim).

Betty also reported that as manager of the team supporting Joan, she and/or any staff supporting Joan were in the best position to judge whether something was wrong with her and then had a duty to persevere on her behalf, even if it meant asking for a second opinion:-

I think perseverance. We were trying to find out what was wrong with this lady and that is a lesson we learned. It is perseverance. Don't let go of it. You know when something is wrong and you stick to your guns and if you've got to ask for a second opinion, then do it (Betty, manager of the team supporting Joan).

There was also a feeling amongst the majority of participants to involve the support of other relevant parties such as other staff and/or family members in an attempt to get their concerns heard. Michelle argued that if staff concerns are not being heard, then enlisting the help of a third party may be beneficial:-

I think the main thing is persistence and asking and pushing to get the information and if you can't get it then get other people involved like the care manager and maybe the family, if there is family available (Michelle, senior social care worker to Graham).

Circumstances where staff felt perseverance was particularly important related specifically to making the GP listen, trying to get accessible information relating to cancer, obtaining a cancer diagnosis and prognosis, and trying to organise palliative care.

Eleven of the 14 staff interviewed were committed to and had provided **continuity of care** to their tenant. Existing literature suggests that cancer patients generally consider continuity of care important (Kendall et al 2006). In reality providing continuity of care required a significant commitment from staff to be available at times when perhaps they ordinarily would not have been. For example, Rachel described the problems she had experienced in having to make changes to a monthly staff rota to accommodate continuity of care for Neil:

I have to have a rota in place. The logistics are a nightmare. An absolute nightmare it is. This is why I said for a longer period it is unsustainable. The staff are very, very good and they will do anything to help, anything at all you know. These people are sleeping on a blow up bed in his lounge. You know because that is what it is. You know you can't ask for more can you? (Rachel, manager of the team supporting Neil).

This commitment to provide continuity of care helps to demonstrate the close relationship they shared with the tenant (see page 180 for further discussion on defining the relationship). These relationships can be complex and can

have long lasting consequences. Findings from the study conducted by Bradshaw and Goldbart (2013) investigating staff views on the importance of relationships with tenants also indicated tensions existed between developing close relationships with tenants and boundary setting. Boundary setting by staff was seen to be an important part of ensuring that staff members were not taken advantage of by tenants and doing tasks for tenants that they were capable of doing for themselves (Bradshaw and Goldbart 2013). Another study carried out by Clegg and Lansdall-Welfare (1995) suggests people with learning disabilities living in residential care are pre-disposed to becoming attached to staff and may develop emotional insecurity as a result of staff not meeting these needs. Staff and tenant relationships are further highlighted in a study conducted by Emerson and Hatton (2008). This study was commissioned by Mencap with the aim to summarise national data source information on the life experiences and services used by people with learning disabilities in England. They reported people with learning disabilities are less likely to have social contact with family or friends than those without learning disabilities. Similarly other studies reported the majority of people with learning disabilities were socially isolated with staff being the main providers of emotional and practical support (Forrester-Jones et al 2006).

In this study some participants commented on how they would not hesitate to provide continuity of care if they were supporting a member of their own family, and so in many ways, their level of commitment to providing continuity of care to the tenant was exactly the same. Whilst tension exists between

staff and tenant attachment and the service organisation culture (Schuengel et al 2010), perhaps it is not surprising that support staff develop close relationships with tenants, and compare them to familial bonds. On the one hand, attachment appears to be an important and vital part of developing positive relationships between staff and tenants and on the other, organisational management and systems require increased objective measures for monitoring quality of care (Reinders 2009).

Michelle explained how the staff team supporting Graham wanted to support him in the same way they would have supported a family member:-

The same way as we would have looked after a family member, we wanted him, we pushed for him to be home but the worst case scenario would have been for him to be left in hospital because he was surrounded by people who really cared for him and we did as a staff team, you know we really did care for him (Michelle, senior social care worker supporting Graham).

One staff member also suggested that having the same staff taking the tenant to and from the GP surgery for appointments, ensured primary healthcare staff within the practice became familiar with the tenant and the support worker and they were therefore less likely to be ignored:-

I think you tend to get further on with the medical profession if it's the same face or the same couple of faces and they are not fobbed off (Janet, manager for the team supporting Jim).

Many participants highlighted that tenants wanted the same staff supporting them. They claimed it gave the tenant something to look forward to and reinforced part of their role identity by demonstrating their '*special relationship*'. This was particularly so when the tenant became ill:-

Having the same team around which we had been for a couple of years then, we had been a constant team because he would look forward to different staff coming in see? We would tell him in the morning you know and he would always ask. Continuity of staff is really important (Bob, social care worker to Graham).

Betty reported that the team felt having agency staff support Joan was not an option:-

I'll tell you my staff team would not have let an agency nurse anywhere near Joan, they wouldn't have, they would not have. Well they'd have killed me if that's what I'd done (Betty, manager of the team supporting Joan).

Staff demonstrated their commitment to the tenant by providing continuity of care. They compared their commitment to the tenant to that of a family member. Whilst at times it was difficult to organise, with other tenants having to adjust to being supported by agency staff, they argued it was beneficial in obtaining the help they needed from primary healthcare services and made the tenant who was ill feel happier. Staff who demonstrated their commitment to their tenant through continuity of care, were able to reinforce their role identity.

Ensuring the tenant was **as comfortable as possible** during their illness was perceived by participants to be an important aspect of their role identity. During the course of the interviews, participants shared the imaginative and dedicated ways they tried to achieve this. During these conversations, some appeared to be proud of the lengths to which they had gone to in trying to make their tenant as comfortable as possible. For example, Betty described how the team had overcome Joan's dry mouth and her lack of interest in drinking fluids:-

One of the memories I've got is that we were there and her mouth was getting very, very dry and so we kept putting Vaseline on and everything on it and what have you and I don't know she wasn't drinking properly and I thought I know and we had these mini milk ice creams. I was sitting there with this mini milk thinking come on Joan we'll have this, you know (Betty, manager of the team supporting Joan).

Betty further described how the staff joined in and tried to provide Joan with special treats:-

She wanted a chocolate so the staff melted it down. Jelly we made her as well, just so that she could have something, just a little bit in because it would dissolve wouldn't it and you didn't have to do anything to it (Betty, manager of the team supporting Joan).

Similarly other staff recalled how they had attempted to make the tenant as comfortable as possible right up to the last moments of their lives. They also expressed pride at being able to provide this comfort:-

I was with him when he died, to the very end. You know and he said he wanted to stay at home, he didn't want to be in hospital and we just made him as comfortable as possible to the last moment. You know, we miss him mind, I've got to be honest (Mary, social care worker supporting Graham).

Residential settings are increasingly expected to deliver palliative care to tenants although how social care workers meet these needs is only recently being explored (Ryan et al 2011, Weise et al 2012, Todd 2013). There is limited knowledge surrounding the palliative care needs of people with learning disabilities, although again, this knowledge has increased quite significantly since 2000 (Tuffrey-Wijne 2007). Issues surrounding the need

for palliative care (Mencap 2004), late diagnosis (Hogg and Tuffrey-Wijne 2008), issues surrounding disclosure of diagnosis and prognosis (Read 1998, Ng and Li 2003, Todd 2004b, Blackman and Todd 2005, McEnhill 2005, 2008, Forbat and McCann 2010) and communication (Hemsley et al 2010, Kyle and Melville 2010, Bekkema et al 2013), pain assessment (Davies and Evans 2001, Foley and McCutcheon 2004, Beacroft and Dodd 2009, Beacroft and Dodd 2010), gaining consent and decision-making (Mencap 2001, Hartley 2005) deserve specific attention within this context. These issues directly impact on the role of social care workers and highlight the importance of committed and well-supported social care staff in residential settings (Tuffrey-Wijne 1998). They also raise questions concerning the tasks social care workers are realistically and increasingly expected to carry out. Particularly those tasks that involve providing healthcare support. Currently, service organisations do not appear to recognise this dimension of the social care worker role. For example, they are not recognised and/or acknowledged on current social care worker job descriptions (see appendix 6).

13 of the 14 participants described how they had gone ***above and beyond the call of duty*** whilst supporting the tenant. They described how they had done more than was required or expected of them and how they wouldn't have had it any other way. There was both an emotional and practical dimension to this. Some staff rearranged holidays or annual leave, some worked extra hours unpaid, some stayed with the tenant long after their shifts had finished and sat with them providing comfort and company. Others

prepared special meals, slept on airbeds beside them, made sure they were available to accompany them on all hospital appointments and involved themselves in funeral arrangements. This display of going above and beyond the call of duty demonstrated their commitment to their tenants, which in turn reinforced their role identity.

The majority of participants in this study expressed their desire to provide palliative care to their tenants. Similarly in other studies (Ryan et al 2011, Todd 2013) support staff reported providing palliative care was a vital part of their role and one they wanted to provide. Participants in the study carried out by Ryan et al (2011) also commented on how, despite having raised staffing levels during necessary periods of providing palliative care, insufficient staffing levels still remained. Staff claimed low levels of staffing compromised the quality of care they were able to provide and reported experiencing significant feelings of guilt as a result of not being able to provide the support they considered the tenant needed. It would seem from the findings in this study, social care workers faced similar experiences and where extra hours were being worked, there were insufficient staffing levels to adequately support the provision of quality palliative care. Having inadequate staffing levels at such a crucial time raises issues surrounding the future funding of social care. Health and safety work regulations and risk management also need further consideration in this regard. Whilst participants did not directly link and/or articulate inadequate staffing levels to health and safety at work regulations and risk management, they indirectly

linked it to their ability to provide good quality care and support to their tenants.

Betty, manager of the team supporting Joan described how she had gone above and beyond the call of duty for Joan by working a double shift, despite not being scheduled to do so:-

I remember the Saturday, the one Saturday I rang to see how she was and they said 'oh she's not good'. I said 'right I'm coming up' and I'd put myself down to do the night, but I went in that morning and stayed there all day and worked all night. But that's what you do, I'm sorry I don't care what anybody says (Betty, manager of the team supporting Joan).

By working a double shift, Betty is demonstrating her commitment to Joan and reinforcing aspects of her role identity. It also illustrates potentially dangerous working practices and highlights how social care workers' commitment to their tenants is being exploited by service organisations and/or the levels of funding that requires care to be provided at minimal cost. This exploitation leaves many social care workers vulnerable to a range of personal and professional risks such as burnout and/or unsafe working practices.

3.4. Special relationship

Many participants commented on the special relationship they shared with the tenant. Some compared them to family relationship whilst others felt they were good friends with the tenant. During the interviews, several recalled happy and sad memories of the tenant. Two staff explained how they felt they had learnt a great deal from the tenant. Having a special relationship seemed desirable to staff and represented a significant characteristic of their role identity.

Five participants recalled ***precious moments*** involving the tenant. During the interview some participants became emotional when they recalled these memories. Whilst all of these memories were positive, participants were reminded of their loss and it left them feeling sad. Bob, a social care worker for Graham recalled how busy they were on their holiday together a while before Graham finally died:-

We were up at seven (Bob laughed). 'Oh where do you want to go today?' Zoo we went, safari, he done fantastic. Railway, all right he was in a wheelchair because he had like clubfeet but he didn't live in a wheelchair you know because he could walk as well. But, err... we took him everywhere we could and right up to about a month before he was.... I'd say, 'you, Sharon holidays and me? Again?'. 'Yeah, yeah' he'd say...

and I am just glad I took him. I am just glad he enjoyed it (Bob, social care worker supporting Graham).

Anna recalled how she thought Jim had started to recover following a humorous event on the hospital ward. Hours later Jim died: -

I had just left there about 3 or 4 pm and he, well he made the ward laugh. They were laughing, joking and all his nurses were just hysterical. Right, and I said 'brilliant, I got him back' and then with that just a few hours later he died (Anna, senior social care worker supporting Jim).

Two participants reported how they had **learnt so much** from their tenant and how grateful they were to him/her for having this opportunity to learn. For example, the knowledge Kelly gained from Joyce had influenced her own behaviour:-

I mean I am really fond of Joyce and she has taught me so much because she never speaks bad of any one and I can get a bit like ... this isn't done right and you know? I have learnt everyone does things their own way and stuff (Kelly, key worker supporting Joyce).

Mary reported Graham had taught her to be more patient, and had also taught her a practical skill. Graham's verbal communication was limited and

he used sign language to communicate with staff and other tenants. Prior to supporting him, Mary had no knowledge of sign language but during this period Graham taught her to sign:-

He taught me a lot. He taught me the signs before I even went on training. He was teaching me and it was like how can I say, not really proud, but it was my thank you to him for what he taught me (Mary, social care worker to Graham).

Mary felt grateful to Graham for teaching her to use sign language and she explained that by being able to support him during his illness, but particularly during the last few days/hours of his life, she was able to say thank you in kind for what he had taught her. In the eyes of many participants, having had the opportunity to learn from their tenants, demonstrated they had a special relationship with them, which in turn helped to reinforce their role identity.

The majority of participants ***defined the relationship*** between themselves and their tenant within a familial context. They suggested that they were their tenants only family and in many cases the only people with whom they had a relationship. Several participants claimed that being perceived as a surrogate member of the family by the tenant was part of their staff role. Similarly in the study conducted by Ryan et al (2011) investigating paid carer perspectives of providing tenants with palliative care, two thirds of participants referred to the tenant they supported as a '*friend*' or as '*family*'

and claimed it was a mutually beneficial relationship. Whilst these close relationships made it emotionally challenging for participants to support the tenant, arguably they ensured the tenants received outstanding support from staff that cared deeply about them.

Betty was still grieving for Joan when she was interviewed. Joan had died almost eight months prior to the interview. Betty described her relationship with Joan as a friendship: -

Err.... (Betty struggled for composure), she was a friend (Betty completely broke down in tears). Sorry...so we had, I would say a very, very good relationship you know. We were friends basically you know when you work for somebody for so many years and you think you are, and as I say we were their families in a lot of cases and you try and keep your professional distance but you have to bear in mind that that's all they've got (Betty, manager of the team supporting Joan).

Apart from one participant who had been working as a social care worker for less than two years, all participants reported service organisations expected staff to keep a professional distance from the tenants. Nurses within a healthcare setting face similar issues and much work has been centred around the emotional labour of nursing in attempts to strike a balance between policy directives and good practice (Hothschild 1983, Smith 1992, Gray 2009, Gray 2010, Kovacs et al 2010). Despite historically there being

a lack of research exploring social care workers' perspectives of their emotional labour, more recently there has been a significant increase and recognition of the emotional component of their role (Fisher and Byrne 2012, Mutkins et al 2011, Ryan et al 2011, Wiese et al 2013, Handley and Hutchinson 2013, Todd 2013).

In this study both of the participating service organisations confirmed that whilst there was no formal policy directive of this type, keeping a professional distance was alluded to in staff induction and training materials. Sterling confirmed this dimension of staff conduct was under review at the time of writing. Therefore, whilst there were no formal policies in place to confirm the need to keep a professional distance, it had become an accepted wisdom between staff and the organisation itself. In practice, participants reported maintaining a professional distance was unrealistic. They argued it was impossible to do their job properly and meet their tenants' needs if the relationship they shared was based on a professional arrangement only. For example, Anna was aware of the required professional boundary but admitted that achieving this was extremely challenging:-

I know they (the service organisation) say you can't get attached to them but when you are practically living with them, it is hard. Because they are your family basically. All the time you are with them and he loved me to bits (Anna, senior social care worker supporting Jim).

Within this study the majority of participants were emotionally involved with the tenants they supported. This emotional involvement was challenging for many participants, particularly when the tenant became ill with cancer. Many felt that not having this emotional connection may have compromised both the welfare of the tenant and the quality of care and support provided. The emotional dimension of this relationship reinforced desirable characteristics of their role identity such as commitment. It also caused conflict with the service organisation philosophy.

3.5. Being strong

Part of the staff role identity related to being perceived as strong. Demonstrating strength, particularly emotional strength when a tenant was ill, was considered an essential aspect of social care work and contributed to the concept of being an effective social care worker. Participants perceived being strong in a variety of ways but these largely centred around managing emotions, keeping busy, getting on with things and displaying a positive attitude particularly when challenges arose.

Some participants believed **keeping busy** was a way of coping with stressful and/or emotional experiences and/or periods. They explained by keeping busy they were able to keep their minds active and away from distressing thoughts. This was important when a tenant had just died and staff were

grieving. When Anna was asked if she felt she needed to take some time off after Jim died, she argued that keeping busy actually helped her to come to terms with his death. She argued that if she had been forced to take time off, she would not have coped: -

When I was on my own I know I did break down several times. And at one point I thought I can't go to work anymore. But I did, I kept going and I preferred to be kept busy and kept going because otherwise I wouldn't have, I don't think I would have coped (Anna, senior social care worker to Jim).

Whilst Anna's comments represent a usual response to the death of someone close, they highlight the emotional relationship she shared with Jim and how she was emotionally affected by Jim's death. Her experiences indicate how the service organisation expected and/or permitted her to continue working without exploring and/or monitoring the effect Jim's death had had on her emotional welfare. There seemed to be a lack of awareness by the service organisation of her grief, which could have compromised her ability to undertake her daily tasks of supporting other tenants effectively and safely.

Whilst some participants claimed ***getting on with it/things*** helped them to cope with the challenges they were experiencing, other staff argued there was no option but to get on with things. Again this indicates a lack of

awareness, guidance and support from the service organisation. Participants also expressed their concern that any indication they gave of not coping, may have resulted in their colleagues assuming they were weak and unable to cope. Being perceived as weak or unable to cope was greatly feared and directly threatened their staff role identity.

Lorna, a social care worker who supported both Ben and Joyce during their illnesses, reported how she just got on with things. She reported that when things became challenging she would never have asked for help for fear of her colleagues finding out and considering her weak: -

I think it is the British stiff upper lip¹. You would feel that you were the weakest one out of your team, going for help. I would worry about other team members knowing I was receiving counselling. They would think you weren't strong enough to cope. You weren't a good carer (Lorna, social care worker to Ben and Joyce).

Some participants were resigned to having to get on with things. Bob gave this impression when asked whether there was anything else he wanted to add to help others understand his situation with Graham any better: -

¹ Demonstrating the British stiff upper lip is to display fortitude in the face of adversity or self-restraint in the expression of emotion.

I don't think so (big sigh); you just get on with things don't you? Do you know what I mean? You take each day as it comes and you see how it is
(Bob, social care worker supporting Graham).

Bob's sense of resignation may have been influenced by the commercialisation of care (Hermesen et al 2012) and its increasing impact on the culture and attitudes of service organisations across the care sector. Many service organisations are functioning businesses and as such are expected to compete financially within a free market whilst also ensuring consumer choice and quality of services to their tenants. As a result many support workers may find their morale, creativity, ingenuity and autonomy compromised in the name of transparent and regulated practice. This results in a loss of motivation, decreased work satisfaction, detachment and burnout (Thomas and Rose 2009, Mutkins et al 2011). Despite Bob's resignation being influenced by the commercialisation of care, it also demonstrates his strength to carry on and as such reinforces his role identity by demonstrating his strength.

Being positive with the tenants was an integral part of the participants' role. Maintaining a positive attitude with other staff members and the tenants themselves helped to demonstrate the participants' emotional strength and their ability to remain positive even when faced with adversity. Tanya reported how staff wanted the best for Joyce during her illness and being positive was an integral part of this: -

I have worked with everyone there and no body has ever been negative in supporting Joyce at all. Everybody wanted the best for Joyce (Tanya, one of the managers of the team supporting Joyce).

Kelly (a key worker to Joyce) argued that adopting a positive approach was essential in ensuring Joyce would cope with the current and future challenges she faced:-

I was optimistic. My thoughts and feelings initially was no matter what, I was going to be there for Joyce and that we were going to get through it and we were going to get through it in the best possible way because Joyce doesn't see herself as ill ever and she never, ever likes to be treated like she's ill. I kind of thought about just being strong for Joyce (Kelly, key worker to Joyce).

Kelly strongly believed the experience of supporting Joyce with cancer had also had a positive effect on her. She felt she had gained much from the experience. By being strong and committed to Joyce, Kelly was also able to reinforce characteristics of her role identity.

3.6. Being professional

Adopting a professional approach demonstrated another key aspect of the staff role identity. There are differing definitions of what constitutes a professional approach (Dodevska and Vassos 2013). Professional behaviour is largely shaped by the employing organisation's norms and discourses (Clouder 2003). From a service organisation perspective, adopting professional behaviour relates to a support worker's knowledge, practical skills and behaviour whereas from a tenant's perspective, adopting professional behaviour relates to a support worker's interpersonal skills (Clarke et al 2009, Hatton et al 2009).

Participants seemed to interpret professional behaviour as providing aspects of both perspectives. They strove to act professionally and also admired it in their colleagues. It was also viewed as a valuable part of their role identity. Doing their job efficiently, ensuring confidentiality and prioritising effectively, were all perceived indicators of staff professionalism. Dimensions of professionalism such as maintaining confidentiality and effective prioritising were challenged when tenants became ill. For many staff, providing dignity in illness and death sometimes challenged their professionalism. These challenges sometimes resulted in participants experiencing role ambiguity as they struggled to perform new tasks (see chapter 4, page 199).

By continuing to meet the needs of other tenants alongside meeting the changing needs of the tenant who was ill resulted in staff experiencing increased levels of pressure. Many participants tried to relieve this pressure by **prioritising** their tasks. Whilst staff were used to prioritising their daily

tasks, when a tenant became ill, participants' decisions surrounding what to prioritise reflected the values they considered important and relevant to their role. These priorities therefore reinforced their role identity by demonstrating their professionalism to their colleagues. For example, Betty argued her priority was clearly to Joan and the other tenants in her care, and stated that her other usual daily tasks such as the paperwork could wait:-

My priority was this lady plus the other three ladies that were there. But, the paperwork can wait, that can wait for another day. If I have got to sit with this lady, I've got to go and sit with this lady. If that's what she wants then that's where I will be (Betty, manager of team supporting Joan).

The concept of '**doing your job properly**' was sometimes subjective amongst participants and there was some divergence surrounding what doing the job '*properly*' actually entailed. Some participants considered providing basic healthcare support and taking responsibility for health related issues constituted part of their role. Others felt strongly that it did not. Within the literature, amongst service organisations and social care workers, there is no consensus concerning providing healthcare support (Reynolds 2008, Taggart et al 2011). Increasingly the social care worker role is defined as facilitating choice and autonomy (Department of Health 2008b). Although it can be argued that providing tenants with healthcare support is a matter of facilitating choice and autonomy (Manthorpe and Martineau 2008). Exploring Tanya's comments (one of the managers of the team supporting Joyce), it is

clear that as far as she was concerned part of doing her job properly involved providing some healthcare support:-

You know you support a client, or a service user to attend the doctors and you arrange for them with key workers and if they have to go to hospital then you arrange things. That's part of your role working with Sterling (Tanya, manager of the team supporting Joyce).

Whereas for Mary, support worker to Graham, providing healthcare support was not part of the social care role: -

I was there when they called the doctor out and he admitted it and said that he had cancer, asking 'does he know?' And he said to me, 'would you sign and tell him' and I said 'it's not my place. You are the doctor, it's not our place to tell him' (Mary, support worker to Graham).

Where disagreement and/or confusion existed, some participants used the team as a way of gauging their approach to tasks and levels of responsibility. For example, whilst Kelly had her own ideas around doing her job properly she reflected she needed to consult the team to gain their approval of her approach: -

I was there to do the best job I could do and that was in agreement. Because I have this well I think this is the way its got to be done and this is my way. In agreement with everyone else is the best approach (Kelly, key worker to Joyce).

Kelly's comments illustrate how she recognised her own strengths and weaknesses whilst supporting Joyce. Whilst she did not explicitly use a framework or model of reflexivity, through a process of reflection she was able to build on her existing strengths and take appropriate action and advice from her team when she needed reassurance concerning the best approach for Joyce. Reflexivity in nursing practice is considered a valuable tool and is a widely promoted and practiced (Somerville and Keeling 2004) but unlike nursing, reflexivity in social care work is not well researched.

The majority of participants reported providing ***dignity in illness and/or death*** was an important aspect of their role for two reasons:- firstly staff claimed it gave them one last opportunity to express their respect and gratitude to the tenant. Secondly it provided staff with the opportunity to demonstrate to their colleagues and tenants their commitment. Similarly in a study conducted by Ryan et al (2011) staff spoke of their sense of achievement when a tenant experienced a 'good' death. By helping to provide a comfortable and pain-free death, staff described how they had felt privileged at having had the opportunity to do their best one last time. Betty, manager to the team supporting Joan, explained how the staff tried their best

to ensure Joan was comfortable and clean regardless of the side effects of her illness:-

Betty: *Well we made sure that she was dressed beautifully everyday, you know and she was in the bed and she wanted to go to the toilet and we got her up, and we put her on the toilet. We did everything she wanted us to do and sometimes she would be soaking wet you know?*

TC: *With sweat?*

Betty: *Yes the perspiration. We cleaned her up, we put perfume on her we did everything. We did her hair you know we did everything as normal* (Betty, manager of team supporting Joan).

For Mary, support worker to Graham, it was important to ensure Graham looked respectable and well cared for when his family visited. She knew it was important to him for his family to see him in a presentable state. It was also as important to her to show the family he was being supported with dignity by committed and professional staff: -

When his family visited, they seen him twice and I think the both times I was on and they commented on how nice he looked and everything in the bed and it was all tidy as if he was in a hospital like. I think that is very nice for family to pass comment on how we cared (Mary, support worker to Graham).

As previously discussed on page 161, when Joyce was ill, at Joyce's request the key workers and managers decided her cancer diagnosis would remain **confidential** from other members of the team until a staff meeting had taken place a day or two later. After this meeting, the other members of the team felt angry and upset they had not been informed of Joyce's diagnosis immediately:-

I was on the night that they diagnosed Joyce and I wasn't told, so I wasn't a happy chappy. I wasn't upset. I was more annoyed because I spent a long time with Joyce being upset but not being aware of what she was upset for because the answer I got was that it will be told in the meeting tomorrow or the next day whichever it would be (Lorraine, support worker to Joyce).

Kelly, key worker to Joyce argued that she wanted Joyce to have the autonomy to decide when she wanted to share her diagnosis and with whom. This raises issues surrounding informed decision-making. If Kelly had explained to Joyce the implications of other staff not knowing her diagnosis then Joyce's decision would have been informed. If Kelly did not explain this, then Joyce's decision would not have been an informed one. It is not clear from the interview transcripts whether Joyce's decision was informed or not. As previously discussed on page 154, Kelly argued that by not respecting Joyce's wishes she would in some way be facilitating action enshrined in the old institutional philosophy and, for Kelly, part of her role identity was

demonstrating a commitment to the principles following deinstitutionalisation and based on the social model of care: -

Joyce didn't want anyone to know about it, she didn't want any of the other clients to know about it. She didn't want friends to know. She wanted to keep it quiet and she wanted to get over it and it be behind her and she didn't want all this sympathy and stupidity. Staff said to me 'well don't you think people have a right to know?' and I said 'no. It's like if you had it Jenny, it's up to you whether' ... and she said, 'well I wouldn't mind' and I said 'but Joyce does, she doesn't want anyone to know. Joyce wants to pretend it's not happening. That's how she wants to deal with it.' So I was really, that was out of my control so that was real stressful... I didn't want the staff to have ownership of it because in institutionalised days that's how they used to be (Kelly, key worker to Joyce).

On employment staff are asked to sign a confidentiality agreement as part of their contract. In practice, participants reported maintaining confidentiality was sometimes difficult to achieve. All participants were aware of the importance surrounding confidentiality and this informed their perceptions of what it meant to be an effective support worker. Amidst the long-standing relationships they shared with the tenants, there were times when they questioned whether retaining confidentiality was actually in the best interests of the tenant and this conflict sometimes created staff stress.

3.7. A reflective account of role identity

From the beginning of data collection and simultaneous analysis, I became instantly aware that social care roles seemed to become problematic when supporting a tenant with cancer. It was clear these changes largely involved the incorporation of healthcare tasks, for which support staff had received no prior training. For me, possibly due to my lack of contact and experience of learning disability services, the concept of a social care worker not providing some healthcare support seemed out of place and I wondered why these roles had not been combined from the outset of deinstitutionalisation and the development of the social care worker role. Upon further investigation I realised that as a result of deinstitutionalisation, service philosophy became enshrined in facilitating tenants based on the social model of disability. To then incorporate aspects of healthcare may have been perceived as a return in part to the philosophy surrounding the medical model and in some ways representative of the institutional days. Once I had grasped these nuances, I was able to firstly understand why healthcare tasks hadn't initially been incorporated in the social care role and secondly, a possible reason for the reluctance by service organisations and others to recognise the need for a healthcare dimension within the social care worker role.

3.8. Summary

This chapter reported on the theoretical category of staff role identity. There is no accepted definition of the role of a social care worker. There is also no requirement in participants' job descriptions to provide healthcare support. Participants constructed their identities through values outlined and regulated by service organisations, through colleagues shared value systems and through their own personal value systems. Experience, commitment, compassion, strength and professionalism provided the framework of the staff role identity and those able to demonstrate these characteristics were considered to be effective at their job. They were the most valued by their teams and their service organisations.

The relationships staff share with tenants are complex. The majority of participants shared close relationships with their tenants, likening them to familial bonds. Whilst service organisations encouraged staff to keep a professional distance, in practice participants felt this was impossible and detrimental to the quality of support they provided their tenants. The majority of participants struggled to manage the emotional component of their work when tenants became ill and/or died. Service organisations seemed largely unaware of these challenges although they appeared to rely on these emotional relationships to compel staff to meet the new challenges supporting a tenant with cancer brought. As a result, these challenges seemed to blur the boundaries of the existing staff role identity and for the majority of participants, appeared to create role ambiguity.

CHAPTER 4

Role Ambiguity

Within this study the concept of role ambiguity directly relates to uncertainty surrounding what should be accomplished in a particular job or role (Matteson and Ivancevich 1982, Chang and Hancock 2003, Tunc and Kutanis 2009). Whilst the majority of participants appear to have experienced episodes of role ambiguity at various stages of supporting their tenants with cancer and discussed and explained confusion and a lack of clarity surrounding their roles, they did not necessarily recognise and/or articulate this confusion and lack of clarity as '*role ambiguity*'.

Social care staff within residential settings are increasingly expected to meet the challenges of supporting tenants with their age related illnesses such as cancer. This study has reported on how this increasing dimension of their work is not recognised by service organisations or represented on their job descriptions. It appears to challenge staff role identities by blurring the boundaries between the tasks they have previously undertaken, such as facilitating independence, and new health related tasks, such as providing post-operative care. These changes appear to challenge their role identity

and create role ambiguity leaving staff uncertain and confused about what their jobs now involve.

This chapter will critically examine how staff experience role ambiguity when a tenant becomes ill with cancer. As staff provide healthcare support, their daily duties change dramatically in ways they may not have envisaged or been formally trained to provide. They attempt to meet the changing needs of the tenant throughout the stages of the illness. For example, they attend additional GP appointments, accompany the tenant for diagnostic testing, gain and make decisions surrounding the tenant's diagnosis/prognosis, support the tenant during treatment and provide post-operative and palliative care.

Table 6 identifies the theoretical category of role ambiguity and its corresponding six focused codes. These focused codes will be explored and critically discussed by sub-heading alongside their respective initial codes, which are highlighted in bold and italics within the text of this chapter. This chapter will close with a summary.

Table 6 Theoretical category and focused codes relating to role ambiguity

THEORETICAL CATEGORY	FOCUSED CODE
Role Ambiguity	Tenants' barriers
	Healthcare barriers
	Knowledge barriers
	Internal barriers
	External barriers
	Communication barriers

4.1. Tenants' barriers

This focused code derives from seven initial codes relating to the barriers tenants either voluntarily erected for their own personal reasons or sometimes inadvertently erected through their lack of awareness and/or comprehension of the seriousness of their condition. These barriers required participants to respond to, and support, tenants in new ways, which challenged their existing role identities and sometimes left them unclear and confused about what their role entailed and how they should perform it. In other words, it left them experiencing role ambiguity.

Of the six tenants involved in this study, none independently alerted anyone that something was wrong. Some tenants tried to carry on as normal, seemingly unaware or ignoring their symptoms. Others became aware of particular changes in their bodies but did not necessarily perceive these as problematic. Previous literature suggests it is not unusual for **tenants' symptoms** to go unnoticed and/or unexplored (Stanish et al 2006, Baxter and Bradley 2008, Emerson and Baines 2010, Emerson 2012, Heslop et al 2013). For example, Jim started to become incontinent but it was his social care worker that noticed and helped him to deal with it. Jim did not question why or voluntarily inform anyone he had started to become incontinent:-

It was just a dribble, you know. It would leave a little wet patch on his trousers and he didn't realise he was doing it and we'd have to say to him, 'Jim, do you want to go?' And whisper to him and he'd go....'oh'. We'd try and calm him and say 'go on, if you need a hand give us a shout' (Anna, senior support worker to Jim).

Similarly it was May, support worker to Joyce, who found the lump on Joyce's breast when she was bathing:-

Well I actually found a lump I did and I mentioned it a bit before and called the management. The manager came with another member of staff and they thought it was, you know, like tissue. Anyway I kept my eye on it and

when I was bathing her, I noticed that her nipple was being drawn in and I could feel it (May, support worker to Joyce).

Literature has highlighted the lack of accessible information on cancer for people with learning disabilities. (Tuffrey-Wijne and Bernal 2003, O'Regan and Drummond 2008, McEnhill 2008). Jones and Tuffrey-Wijne's (2007) study suggests this is due to a lack of understanding of the cancer information needs of people with learning disabilities in conjunction with issues surrounding communication. More recent studies have clarified these key issues (Tuffrey-Wijne et al 2010, Tuffrey-Wijne 2010, Bekkema et al 2013). Organisations such as Macmillan Cancer Support, Cancer Research UK, and Palliative Care for People with Learning Disabilities Network (PCPLD) have produced a variety of resources accessible to people with learning disabilities and their carers. For example, CHANGE, a leading national human rights organisation led by people with learning disabilities, has joined forces with Macmillan Cancer Support and developed a series of information books about cancer specifically aimed at people with learning disabilities (CHANGE 2010).

Confusion still exists surrounding who is actually responsible for accessing and delivering cancer information on behalf of, and to people with, learning disabilities. The majority of participants in this study did not see accessing and delivering this information to the tenant as part of their role. This confusion directly impacted on tenants' access to cancer information and may, in part, help to explain why barriers to cancer information for people

with learning disabilities still exist. (The participants' information and support needs, and their delivery and dissemination of cancer information to people with learning disabilities is further discussed on page 236).

Some participants suggested the ***tenants did not understand*** they had cancer or were seriously ill. Treatment options may be restricted, delayed or even denied if a tenant is not informed of their diagnosis and/or prognosis. Issues related to decision-making and the Mental Capacity Act (2005) exist. Whilst the Mental Capacity Act (2005) does not cover all decisions it does encompass serious medical treatment. If capacity is lacking, a decision should be made in the tenant's '*best interests*' by interested parties including, where possible, relatives (O'Regan and Drummond 2008, Tuffrey-Wijne and McEnhill 2008, Bekkema et al 2013).

Some participants in this study argued that informing the tenant of their diagnosis/prognosis was inappropriate. Several participants claimed the tenant would not have coped with the news. During the interviews there was no mention of capacity assessments taking place or decisions being made in the tenant's best interests. Evidence suggests that many people with learning disabilities want to be informed of their diagnosis (Hogg et al 2001, Jones, Tuffrey-Wijne et al 2007, Tuffrey-Wijne et al 2010, Wagemans et al 2013). In the study conducted by Creswell and Tuffrey-Wijne (2008), Creswell discusses her own experiences of having a learning disability and cancer and how important it was for her to know and understand what was/and would be happening to her. As previously discussed on page 157, again there is

tension between promoting tenants' autonomy and protecting a tenant from harm. Arguably some social care workers may not be aware these decisions constitute a crucial part of their role and may not be adequately equipped and/or independently best placed to contribute to making these decisions, particularly considering the sometimes emotional dimension of their relationships with tenants. On the other hand, some may consider contributing to these decisions are an important part of their role. It is also possible that support staff incorrectly assume that healthcare staff are responsible for making these decisions.

Of the six tenants with cancer, participants stated three tenants did not understand what cancer was, claiming it was better this way. For example, Anna senior support worker to Jim, explained even though Jim had been told he had cancer, he did not understand what cancer actually meant and that she was glad he lacked the capacity to understand his diagnosis:-

But he knew he was ill. He didn't like it but he didn't, I don't think he understood thank God in a way. He didn't understand exactly what... he knew he had a lump and it was nasty but that's all he knew. He was told but he couldn't understand it, which I'm glad about in a way because I don't think he would have coped otherwise (Anna, senior support worker to Jim).

Whilst Anna was sure Jim did not understand the meaning of cancer, it is possible he decided he did not want to engage with the subject of his cancer. Many people receiving a cancer diagnosis voluntarily choose not to discuss cancer and/or even acknowledge its existence.

Kelly, key worker to Joyce, requested Joyce was not informed of her diagnosis, arguing that she lacked the capacity to understand her diagnosis at that time, although it appears no formal assessment of capacity or a best interests meeting had taken place:-

We said to them 'don't mention the cancer because Joyce won't be able to comprehend that in this environment at the minute'. Then they spoke to Joyce and they said 'Joyce you will need an operation and this is what we are going to do' but they never said you've got terminal cancer or anything like that to her and then when we got back we explained and she kept saying 'I don't want an operation, I'm not having an operation' (Kelly, key worker to Joyce).

Kelly refers to Joyce's cancer as terminal, despite Joyce being diagnosed with breast cancer and being offered a mastectomy. This confusion concerning Joyce's diagnosis is discussed later on page 266.

Bekkema et al's (2013) study highlighted the barriers support workers and/or caregivers encountered in respecting a person's autonomy. They were

diverse and largely related to the person's cognitive ability. For those people with severe learning disabilities, they argued it was hard to determine their support needs, but in those with milder learning disabilities, they found support workers' and/or caregivers' overriding concern was not to upset the person. In practice there is a huge spectrum from facilitating an individual's autonomy from deciding what they would like for supper to deciding whether they want to have chemotherapy. In a recent study by Ryan et al (2011) investigating the perspectives of support workers on palliative care for people with learning disabilities, staff reported decision-making on issues connected to palliative care stressful and challenging. Whilst they felt their knowledge of the tenant equipped them to make a valuable contribution to the process, they equally felt they lacked the skills and knowledge in some areas to make/contribute to effective and adequate decisions and were sometimes left feeling distressed at their lack of, or actual input into, the decision-making process (Ryan et al 2011).

It would seem that staff want to be involved in the decision-making process and as a result of their relationships with tenants believe they can make a valuable contribution. However, they feel under-equipped to provide this type of support and do not feel they have the knowledge and skills to be effective. They also seem largely unaware of their existing responsibilities in this regard. This leaves them feeling distressed. Their lack of knowledge and skills alongside the lack of clarity surrounding their role in decision-making processes has left them experiencing role ambiguity.

Participants reported changes in the ***tenants' behaviour*** when they became ill. A change in behaviour by people with learning disabilities in response to feeling unwell is well documented in the literature (Foley and McCutcheon 2004, Beacroft and Dodd 2009, 2010, Findlay et al 2013). Despite tenants not being informed of their diagnosis/prognosis, participants became conscious of the tenants' awareness that something was changing and/or something was wrong. For example, Bob, support worker to Graham, recalled how Graham suddenly took an interest in attending the day centre. Bob claimed Graham wanted to say goodbye to his friends. Graham also started to remove his photographs from his wall and put them away. Bob thought Graham's behaviour was strange, particularly as Graham was never officially diagnosed or told he had cancer.

This raises two issues; firstly it is not clear what Graham knew and understood about his condition and it may have been more frightening for him to speculate what was wrong with him. Secondly, he may have suspected his illness was serious, which from the evidence above it seems likely that he did, although there is no way of knowing how he felt about what was happening to him and what his understanding was of death and dying. It is not clear from participants why Graham was not informed of his diagnosis and prognosis over and above their opinion that it was for the best, although it is not clear for whom it was actually best. Again, arguably, social care workers may not be best placed, equipped and/or adequately trained to make these decisions, particularly as it remains unclear on what basis these decisions are made.

These changes in behaviour were not only restricted to the tenants with cancer, but sometimes involved the reactions of other tenants living in the same house. Betty, manager of the team supporting Joan, experienced a difficult period with one of the other tenants, Dorothy, after Joan's death. Dorothy was in her eighties and had never displayed challenging behaviour before Joan's death but after Joan's death her behaviour became so challenging she had to eventually be removed from the house and admitted to a psychiatric hospital. At the time Betty did not connect Joan's death with Dorothy's behaviour but, latterly, Betty is convinced Dorothy's behaviour changed as a direct result of the grief she was suffering following Joan's death.

Arguably the grief Dorothy experienced at the loss of a longstanding friend with whom she had lived with for many years is not surprising and any close friend or relative in this situation would have experienced a significant loss. The social care workers had not considered Dorothy's grief. This situation may have escalated because staff had not encountered this situation before and did not recognise Dorothy's bereavement needs. They were not aware of, and did not respond to, her needs and this may well be because they themselves were not aware of this increasingly new dimension and responsibility within their role. This lack of clarity surrounding their role of needing to be aware of and respond to other tenants' bereavement needs indicates staff were experiencing role ambiguity. This role ambiguity appeared to directly impact on Dorothy's wellbeing and significantly delayed the support she needed.

Previous research has identified that the grief experienced by marginalised groups such as people with learning disabilities is often ignored (Doka 1989, 2002). Doka (1989) suggests this is because the relationship is not recognised, the loss is not deemed to be significant and the person suffering from grief is not perceived as being capable of experiencing grief. Doka (2002) argues the ways in which individuals express their grief and the circumstances of the death also contribute to why grief within the learning disability population is largely ignored. These attitudes, alongside service organisations inadequate approaches to death and dying (Todd 2004), have left support staff unprepared and lacking the skills and knowledge required to adequately support tenants (Read and Elliott 2007).

Some participants commented on their ***tenants' fear***. Many older people with learning disabilities may have experienced living in institutional settings (see page 153 for further discussion on institutional days). For some this exposure to a medical environment may have created familiarity with a medical environment and reduced their fears. For others this, alongside exposure to surgical intervention relating to their learning disability, may have left some people with learning disabilities fearful of medical environments. For example, Joan hated hospitals and doctors and would become anxious at the mention of anything medical. Joan's reaction related to her earlier experiences of hospitals where she underwent a series of surgical procedures relating to her learning disability. This fear impacted on tenants in a variety of ways and may account for their reluctance to acknowledge changes in their health. At times social care workers noticed significant

changes in their tenants' behaviour, which inadvertently alerted them that something was wrong. For example, Betty knew that Joan would not tell her if she felt ill or was in pain because she was afraid of doctors and hospitals:-

It was because she didn't identify pain or had a fear of doctors and hospitals and everything. She wouldn't tell you if she was unwell. I mean she would never tell you that she was ill. You had to judge that for yourself. She was ill before that but never showed it to us (Betty, manager of the team supporting Joan).

This is complicated further when a tenant has poor communication or is non-verbal (Jones et al 2007, O'Regan and Drummond 2008). In these situations continuity of social care staff, alongside social care workers' awareness of the possible links between behaviour changes and illness, is vital in ensuring the tenant is understood and changes in their behaviour are recognised and understood in a timely way. Therefore, social care staff need to be clear of their responsibility to look for changes in their tenants' behaviour and the possible links between behaviour changes and illness. This lack of role clarity again indicates role ambiguity.

The fear some people with learning disabilities experience surrounding medical involvement based on their earlier experiences, contributes to the usual fear and apprehension many people generally experience when undergoing surgery. This **reaction to surgical intervention** can result in

medical environments and interventions becoming particularly challenging for both tenants and social care workers. May, support worker for Joyce explained how frightened Joyce became prior to her mastectomy:-

I said 'now Joy, now listen we've been friends for years haven't we?' and she goes 'yes you're my friend' and I said 'well please Joy if you're worried or concerned or upset about anything' I said 'don't you keep it to yourself'... She said 'I'm frightened', she said, and I go 'oh Joy' and I put my arms around her and said, 'don't be frightened you'll be all right darling.' But I was so glad that she felt able to speak to me (May, support worker to Joyce).

Joyce was aware and frightened of her impending surgery and May, having known and supported Joyce for over 25 years, was pleased that Joyce could share her fear with her in a way that enabled her to help Joyce through what was clearly a fearful time. May's comments demonstrate how vital it is for social care staff to be mindful of, and adequately prepared for, tenants potential reactions to surgical intervention. This new dimension of their role requires clarification to eliminate potential role ambiguity and ensure they receive adequate training and support to meet their tenants' needs effectively.

Some tenants **refused treatment**. Kelly, key worker to Joyce, and the rest of the team were able to persuade Joyce to have treatment, but both Joan

and Jim refused treatment, despite continual attempts by staff to persuade them to undergo treatment:-

We had a phone call just after.... literally after the Christmas holidays to say you need to come for this procedure. Well she had already said that she didn't want anything that she didn't want to do anything because she just held her hands up and said 'no'. So you have to grant her wishes don't you? (Betty, manager to the team supporting Joan).

Again this raises important issues surrounding participants' understanding of the Mental Capacity Act (2005) (see page 204 for previous discussion). This was of particular concern as both Jim and Joan were not informed of their diagnosis and/or prognosis based on their lack of ability to comprehend their cancer diagnosis/prognosis and yet it appears from the data, they were deemed to have the capacity to make the decision not to have cancer treatment.

Similarly, the Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD) (Heslop et al 2013) highlighted a lack of assessment and supporting documentation when determining capacity of the cases reviewed. It also identified concern over the '*best interests*' process including delays in convening meetings, confusion concerning who should be leading the meeting, misunderstandings relating to the process and poor recordings of decisions.

Some participants suggested the ***tenant could not cope*** and argued that the balancing act between the tenant's refusal of treatment, the tenant's best interests (as far as the support worker perceived them) and the tenant's previous experiences, made supporting the tenant to reach a decision in a way they could comprehend and cope with, extremely complex. For example, Kelly knew Joyce had already experienced some mental health problems, but also knew Joyce did not want to go into hospital and undergo surgery. According to Kelly trying to achieve a positive outcome for Joyce in a way she would be able to cope with required significant thought, team commitment and a planned approach:-

We were all very gentle around her, because she had had a breakdown a few years before '.....' A very small group of us work with Joyce so we all relay the same thing, so she didn't get mixed messages, she didn't think any one was lying so we didn't really tell Joyce initially that she had cancer. We said that she had to have this operation to remove the '.....' And then we would take it from there. You as a carer, you have to adapt to what's best for them and if you get emotional with Joyce or over emotional she panics (Kelly, key worker to Joyce).

4.2. Healthcare barriers

Eight initial codes combine to create this focused code. These initial codes represent barriers involving either healthcare staff and/or the medical environment. Again, in common with the previous focused code of '*tenants barriers*', healthcare barriers required participants to respond to and support tenants in new ways. These new ways challenged participants' existing role identities and sometimes left them unclear and confused about what their role now entailed and how they should perform it.

Of the six tenants with cancer, four tenants and their social care workers experienced ***unsupportive GPs***. This was particularly so concerning the investigation of the tenants' symptoms. For example, Anna reported she visited the GP with Jim on numerous occasions to share her concerns. She was continually told by the GP there was nothing to worry about. This had grave consequences for Jim, who eventually received a cancer diagnosis (Anna received the diagnosis on Jim's behalf) so late that his only option was palliative care. Anna was frustrated and angry but also desperately sad at Jim's outcome:-

I had my suspicions for months but we were pushing the doctors, the GP and we were just pushed aside all the time. The doctor just kept saying 'he's got plenty of weight to lose', but there wasn't, when you looked at him you could see that he was really ill. His colour changed, he wasn't eating, he was in a lot of pain but the doctor just wouldn't deal with it and in the end when he was eventually diagnosed they said that all you can do now is palliative care. They did refer us to the oncologist to see if he had

the same agreement but he had the oncologist appointment at the beginning of January but he died before that. So he didn't even get to his first oncology appointment. It was awful. It was horrible. It was a killer (Anna, senior support worker to Jim).

Betty experienced similar challenges with Joan's GP who, again, refused to accept something was wrong. Betty claimed the GP was ignorant of the issues people with learning disabilities encounter and stated that many GPs struggle to communicate effectively with people with learning disabilities. Sue, manager to the team supporting Graham, explained they too had been going back and forth to Graham's GP with health concerns. Again the GP refused to act on their concerns until by chance on one visit they saw a different GP who finally took their concerns seriously and made a referral for further investigations.

Issues surrounding the input and behaviour of GPs towards people with learning disabilities and their health status is well documented (Lennox et al 1997, Lennox and Kerr 1997, Lennox et al 2003, Mencap 2004, 2007, Hogg and Tuffrey-Wijne 2008, Tuffrey-Wijne 2010, Brown et al 2012, Heslop et al 2013, Jensen et al 2013, Perry et al 2013). The report by Mencap in 2007, '*Death by Indifference*' followed Mencap's initial report '*Treat Me Right*' (2004) exposing institutional discrimination amongst NHS staff and practices towards people with learning disabilities. An Independent Inquiry (Michael, 2008) followed, recommending the establishment of a Public Health Observatory for people with learning disabilities and in 2013 a confidential

inquiry into the premature deaths of people with learning disabilities (CIPOLD) (Heslop et al 2013) was published. Whilst GPs constitute only one part of the patient healthcare journey, they are gatekeepers in obtaining a timely diagnosis, potential treatment options and a positive outcome for the patient.

Many people with learning disabilities may be unable or ill equipped to challenge their GPs decisions concerning their health status and treatment pathways. For the majority living in residential settings, challenging the GP becomes the responsibility of the tenant's social care worker. Social care workers are increasingly expected to act as healthcare advocates on behalf of their tenants. The majority of participants interviewed in this study seemed confused and unsure whether being a health advocate on behalf of their tenant was actually part of their role. For those who considered it was, they were additionally, unsure how far they could challenge a GP. This may well reflect the symbolic power of the medical role and how this structures interaction. For example, Foucault (1975) claims the medical discourse is extremely powerful and defines, organises and controls human bodies from birth to death. This is sustained and maintained by the medical profession who through gaining medical knowledge and practices have displaced the previously dominant religious discourses of centuries past. Foucault perceives medicine as a powerful means of social control and discipline. Illich's (1997) work surrounding the medicalisation critique also supports this view but takes it further by claiming becoming '*medicalised*' denies individuals the opportunity to act rationally and independently by allowing an

authoritative group, such as the medical profession, to dictate how they should behave.

In two separate cases, social care workers relied on a third party (another health professional such as a speech and language therapist) to challenge the GP on their behalf. This confusion and lack of clarity surrounding the role of social care workers to act as health advocates on behalf of their tenants demonstrates further role ambiguity and raises serious concerns surrounding the rights of people with learning disabilities.

Following the GP referral, Graham attended his hospital appointment and underwent further investigations. However, healthcare staff and medical professionals at the hospital were vague concerning his diagnosis. No formal diagnosis/prognosis was received until it was too late. The issue of **late diagnosis** is well represented in the literature (Mencap 2004, 2007, Hogg and Tuffrey-Wijne 2008, Tuffrey-Wijne 2010, Heslop et al 2013). The most recent finding by CIPOLD (Heslop et al 2013) reported that of the 238 deaths of people with learning disabilities reviewed, 42% were assessed as being premature with the most common reason for death being delays or problems with diagnosis or treatment.

After Graham's initial investigations, (Graham attended a scan in 2008), the hospital consultant advised Sue they needed to start thinking about palliative care. During the research interview Sue confirmed Graham did not receive

a cancer diagnosis and reported there was ***vagueness surrounding any diagnosis and/or prognosis*** until shortly before he died from secondary liver cancer in 2010. The primary cancer was never discovered:-

We went on the appointment and I think he had a scan done and we went on the appointment to get the results and they couldn't find anything. The consultant was saying to us that due to his age and things and, you know, his general health at the time, that they felt there was no sort of mileage in any further exploratory tests for him at that time. They said that's when we needed to start thinking about palliative care (Sue, manager to the team supporting Graham).

Sue went on to explain during this period Graham would have episodes of being unwell. He would be admitted to the hospital only to be discharged a day or two later with the hospital consultant stating there was nothing further they could do and he (Graham) was better off at home with 24 hour support. The social care workers supporting Graham would then have to call the GP back out because Graham would deteriorate again and so this cycle continued for approximately two years. During this period Graham presented with blood in his faeces, a lump on his body, a reduced appetite and subsequent significant weight loss. According to the staff supporting Graham, he was in his sixties and whilst he had problems with his mobility and had a hearing impairment, his general health prior to these symptoms was good. When participants were asked why a formal diagnosis was not received until any potential treatment options were not viable, they did not

answer. Michelle, senior support worker to Graham, did say that she felt if she had been a member of Graham's family she could and would have pushed the medical professionals harder for clarity of Graham's diagnosis. Both Michelle and/or Sue did not consider it was part of their role to insist on receiving a diagnosis for Graham's condition.

During the interview when Sue was asked what or who had been the most helpful to her during Graham's illness, she explained getting the actual diagnosis had been the most useful:-

Well the most helpful thing was getting the diagnosis and getting the nurses. (Sue is referring to support from the district nurses). That was what made the difference until that happened I was just running around not knowing where to go and who to pester next. But as soon as we got those in, it was kind of like, you know, you could breathe again and plan and start to ask. You know you had somebody to ask your questions to. Before that all the questions you were asking everybody but nobody could answer (Sue, manager to the team supporting Graham).

With vagueness surrounding an actual diagnosis or late diagnosis and no clear prognosis being provided, **treatment** options become severely restricted at best and non-existent at worst. This was clearly the case for all six of the tenants discussed in this study, who experienced poorer outcomes as a result of late diagnosis.

According to a study conducted by Black and Hyde (2004) investigating the care for people with learning disabilities with colorectal cancer, the perceived rather than actual complications associated with obtaining consent for treatment from people with learning disabilities left medical staff reluctant to offer the same treatment options to people with learning disabilities as those offered to the general population (O'Hara and Sperlinger 1997, Cumella and Martin 2000). Whilst that study was conducted prior to the development of the Mental Capacity Act (2005), the findings of the current study indicate that the Mental Capacity Act (2005) may not have totally resolved this problem. The lack of accessible information concerning treatment also hinders treatment pathways for people with learning disabilities (Jones et al 2007, O'Regan and Drummond 2008, Dinsmore 2012). Communication difficulties and a general lack of awareness concerning the availability of specialist services to help people with learning disabilities and staff with communication barriers, also deter some medical and healthcare staff from discussing issues around diagnosis and treatment options with the person with learning disabilities (Jackson and Read 2008, McEnhill 2008, Tuffrey-Wijne 2009).

Even with Joyce, who underwent a mastectomy, there still appeared to be no clear treatment plan. When participants supporting Joyce were asked during the interview whether there were any plans to follow Joyce's surgery with a course of radiotherapy or chemotherapy, participants did not know:-

I think it was deemed that it wasn't going to do her any difference for her condition and what have you and that's why.... I don't quite understand

whether...because we were told it was terminal in the beginning and there has been some confusion over the prognosis so I don't know (Lorraine, support worker to Joyce).

Whilst Joyce was offered a prosthetic breast after her mastectomy, at no time was she offered reconstructive surgery or was reconstructive surgery discussed. Effective health advocacy may have ensured Joyce received the treatment options she was entitled to.

Inadequate facilities for treatment such as structural and environmental barriers also caused serious issues for some tenants. Joyce used a wheelchair and two members of her support team reported problems with getting the wheelchair into the consulting and treatment rooms at the hospital. Participants expressed their concern on the impact this had on Joyce and how it had compromised her right to privacy. Despite participants knowing and voicing their concerns during the interview, at the time, they seemed unable to effectively exercise their role as health advocate and demand her right to privacy be respected.

One participant also reported inadequate facilities for providing palliative care. Rachel, manager of the team supporting Neil, argued that Neil's needs fell in between service provisions and were therefore not being met:-

Palliative care is very difficult. He is target support and lives independently. Then you've got care homes out there and if they are not dual registered they can't take people with a learning difficulty. So the gentleman is in a bit of a no man's land. OK. We did see if there were any beds up at a local hospice but the beds are full there (Rachel, manager of the team supporting Neil).

Target support is when a person lives in their own home rather than a residential home but receives daily and/or weekly visits from support workers who provide daily/weekly support such as help with shopping, cleaning, washing and dressing. At the time of interview, social care workers continued to provide Neil with target support. Neil was terrified of dying alone and so his social care workers developed a rota and took turns to sleep on an airbed in Neil's front room during the night. These social care workers had not provided this type of support before and Rachel expressed her concern that from a long-term perspective it was unsustainable and emotionally challenging for all the staff involved. None of the support staff had prior palliative care experience or training and whilst they were totally committed to providing this care for Neil, they were unsure whether they were equipped or able to provide effective palliative care. At the same time, as a result of the emotional dimension of their relationships with Neil, they felt compelled to provide the best support they could at such a crucial time and tried their hardest to meet his changing needs. This lack of experience, training and clarity surrounding their role in providing palliative care left many staff vulnerable to experiencing role ambiguity (See page 254 for further

discussion on the other issues social care workers experience when providing palliative care).

Being in hospital can create challenges for the tenant and may lead to further role ambiguity for the social care workers involved. The majority of participants argued that healthcare staff were under-equipped to support a person with learning disabilities in hospital. Participants claimed healthcare staff had limited awareness and/or experience of people with learning disabilities and did not value or use the resources they (support staff) could offer. For example, some people with learning disabilities are unable to communicate verbally. The support workers understand the way tenants communicate and can help healthcare staff to communicate with their patient.

Within this study there were several instances of good practice reported during a tenant's stay in hospital. Several participants reported two tenants received positive support and care from healthcare staff. Despite being kept waiting at the hospital when Joan attended for investigations, Betty reported how supportive and responsive the hospital team were to Joan and how, when the consultant did arrive, he supported Joan into the operating theatre:-

He was brilliant. He didn't put a gown on her and I said to him I want to be the last person she sees and the first person she wakes up to. He walked her down the corridor, hand in hand. Oh it was lovely. This gentleman

really, really understood you know? (Betty, manager of the team supporting Joan).

Equally, Joyce also received support and understanding when she attended hospital for her mastectomy. May described how the hospital staff dressed her toy monkey in a gown and put a drip in the monkey's arm to help allay her fears:-

She has got like a monkey and she loves this Jacko and she took him to hospital with her and they were marvellous with her at the hospital. The anaesthetist said to her 'right and Jacko's coming as well.' They let her take him in and put a hat on the monkey when she came out of the operation. They put a gown on it and made her bed and when she came out he was dressed like Joyce. They put a drip in the monkey's arm like she had; honestly they were absolutely marvellous in hospital. They were marvellous (May, support worker to Joyce).

Following the Disability Discrimination Act (1995), (2005) and the Equality Act (2010) all disabled people including people with learning disabilities are entitled to equal access to public sector services such as hospitals. Public sector services have a legal duty to make '*reasonable adjustments*' to accommodate their needs (Hatton et al 2011). Reasonable adjustments include providing flexibility in the way in which services are delivered and removing physical barriers to accessing services. Whilst a recent survey

exploring the progress of the NHS highlighted instances of good practice, it also identified that an adequate standard is yet to be achieved (Hatton et al 2011). Whilst there is still work to be done in improving practice, it is encouraging to report good working practices within this study. These findings demonstrate that effective joint working practices are possible. Furthermore, health advocacy could also play a vital role in ensuring services make *'reasonable adjustments'*.

Participants reported issues surrounding healthcare staff disclosing information concerning the tenant to the tenant's next of kin. Under the Mental Capacity Act (2005) healthcare staff should not regard people with learning disabilities as lacking capacity and disclose confidential information about them to their relatives or anyone else without their consent. Of the six tenants with cancer, two had regular contact with one family member. One of those family members had learning disabilities themselves and the other was an in-law. In all cases, participants stated they had welcomed the involvement of the tenant's family. They also reported they were prepared to act as the tenant's next of kin and in their best interests concerning their illness. It seems at no point did the tenant, the tenant's family or the service organisation formally pass this responsibility to any of the participants. All of the participants within this study were unclear as to the rights afforded to the next of kin and what their position, role and involvement was concerning acting as the tenant's next of kin. Similarly healthcare staff did not understand the nature of the relationships participants' shared with their tenants. It seems that healthcare staff did not, and arguably could not,

assume the role of the social care worker was one of next of kin. This created a significant communication vacuum between the tenants, social care workers, relatives and healthcare staff particularly within the hospital environment. This issue is also reported in the CIPOLD findings (Heslop et al 2013). Bob demonstrates his lack of awareness concerning the next of kin's right to information and describes his frustration at not being able to get information from healthcare staff on Graham's behalf:-

I understand there's confidentiality but at the end of the day his family lived in Birmingham, his sister up there, we were the ones who were dealing with him on a daily basis and it was just....Even though she was his next of kin obviously for his lifetime he has been institutionalised and then he came out into the community and he's seen us far more than her like. And it was quite frustrating I felt that we couldn't get this answer off them what it was. Whether it was his diabetes you know? (Bob, support worker to Graham).

Michelle, senior support worker to Graham, also expressed how the hospital just did not understand the relationship social care staff had with the tenant:-

I felt all the way along the line that if Graham had been, say he'd been my father, I could have asked and I think they would have given us the information we needed rather than, they were a bit, I felt they were a bit dismissive of us because we weren't family, we were just care staff. I

don't think they truly understood the situation and how close we come to our clients (Michelle, senior support worker to Graham).

Again, participants seemed completely unaware of the requirements outlined in the Mental Capacity Act (2005) and how, even as relatives, until the person is assessed and deemed not to have capacity, they were not entitled to demand confidential information concerning the tenant's health from the healthcare staff without the tenant's consent. Furthermore, this also demonstrates the lack of awareness of both healthcare staff and support staff of each other's roles.

This lack of communication and understanding between support staff and healthcare staff also contributed to many participants feeling disrespected and undervalued by healthcare staff. Anna, senior support worker to Jim, stated there was a ***lack of respect for social support staff***. Anna argued the healthcare staff would not listen to her or other members of her team because they were support staff:-

They wouldn't listen to us because we are just support workers; we are nothing to them like (Anna, senior support worker to Jim).

Janet, manager to the team supporting Jim, also expressed her dissatisfaction at the attitudes of healthcare staff to social care staff:-

They look at us carers as that's what we are carers. We don't know anything, you know? Regardless of the fact that we are with these people 24/7. They are arrogant. You walk through that door and you are a number (Janet, manager of the team supporting Jim).

A previous study by Workman (1996) investigated how healthcare assistants perceived their role as support workers to qualified healthcare staff. This study identified how nursing staff viewed the healthcare assistants as a threat to their own roles by depriving them of their 'real' nursing roles and exposing them to a process of 'role deprivation' (Kramer 1968). Similarly healthcare staff may feel threatened by the specialised knowledge and insight social care workers have of their tenant when they accompany them to hospital. Healthcare staff that feel threatened in this way may express poor attitudes to social care workers in an attempt to undermine them and devalue their presence. Alternatively, it may be that healthcare staff are simply unaware that social care workers lack healthcare training.

The ***timeframe of the tenant's illness*** had a significant impact on the participants. Anna felt angry and frustrated with the GP for not listening and acting more quickly on the concerns she continually raised about Jim. Anna reported immense feelings of guilt after Jim's death. She felt she should have done more to make the GP listen. This guilt was shared by ten of the fourteen participants and will be discussed in more detail on page 292.

Participants commented on how they would have been willing to, but in reality could not, sustain a longer period of supporting the tenant during their illness. For example, Betty argued:-

I don't think we could have done it over a long time. It was very intense. The diagnosis being the pancreatic cancer and everything, it was a really bad cancer and although every cancer is bad isn't it? But I think if you had to sit there and watch that person deteriorate over a longer period, it would be really, really bad and you think, God that wasn't real (Betty, manager of the team supporting Joan).

As previously discussed on page 166, work stress is created when the demands of the role exceed the resources of the individual to do the job (Folkman et al 1987). According to Mutkins et al (2011), a portion of staff will report burnout symptoms, which have significant implications for tenants, colleagues and service organisations. These implications include poor work performance, negative interactions with tenants, staff turnover and a general decline in the quality of service provided to tenants. Ensuring staff are adequately trained and supported and experience minimal work stress can only be beneficial to all involved. In this study social care staff appear to have been exposed to high levels of work stress and service organisations did not seem to be aware of the potential consequences of this exposure.

4.3. Knowledge Barriers

This focused code consists of five initial codes that combine to indicate knowledge barriers. Knowledge barriers concerning learning disabilities and the needs of people with learning disabilities were present amongst medical professionals and healthcare staff. So too were levels of general ignorance, prejudice and discrimination. Social care workers are in a position to challenge these attitudes on behalf of their tenants. In reality whilst participants expressed their concern regarding these attitudes, they did not challenge them. This may be the result of their own confusion and lack of training surrounding their role.

Levels of ignorance and a lack of ***awareness of learning disabilities*** were visible amongst healthcare staff. For example, Betty suggested there is a general lack of knowledge and understanding from healthcare staff concerning people with learning disabilities. Betty also stated if Joan's GP had had a better understanding of her learning disabilities, she may well have presented the treatment options to Joan in a more comprehensive way which may have encouraged Joan to seek treatment:-

I think that if anything comes out of it (this study) that you could improve, is the knowledge and the understanding that the outside professionals, the hospitals, the doctors, have. I wish they had a better understanding of learning disabilities. Even the GP, I mean the GP said in the first instance,

you know when she said there was a mass, she explained to Joan, that was the day I wasn't there, and she said 'Joan I will now respect your wishes', but I think if she had a bit more insight into the lady, in that she could have put it in a different way, that lady wouldn't have held her hands up and said 'no, no, no' (Betty, manager to the team support Joan).

Betty's comments highlight how the GP seemed unaware that there was a need to present information in ways that are accessible so that they maximise an individual's capacity. Betty went on to discuss how important the hospital passport² is when a tenant is admitted to hospital but felt it was used effectively by the hospital staff that did not always appreciate its importance:-

They don't read it and you know they don't read it and even speaking from experience, I know that staff (social care workers) were passing on information but they (healthcare staff) weren't passing it on to the next member of staff. It gets lost (Betty, manager of the team supporting Joan).

² Hospital passports provide hospital staff with important information about the person with learning disabilities and their health. On admission to hospital, they aim to help healthcare staff understand the needs of the patient quickly.

Betty also argued people with learning disabilities sometimes struggle to understand those with unfamiliar accents and when hospital staff have different accents, it becomes even more challenging.

Another participant claimed healthcare staff needed training to raise their awareness of the issues surrounding people with learning disabilities:-

I think a lot of people out there need training with people with learning disabilities (Rachel, manager of the team supporting Neil).

There is a variety of research investigating and reporting on the difficulties people with learning disabilities and their carers experience with both primary and secondary healthcare (Lennox et al 1997, 2003, Sowney and Barr 2004, Melville et al 2005, Langan et al 2007, Backer et al 2009, Brown et al 2012, Dinsmore 2012, Wilkinson 2012). Issues include healthcare staffs' lack of awareness surrounding learning disabilities, poor communication, time constraints, negative attitudes by staff and a lack of flexibility within the healthcare environment. These combine to create barriers to adequate health provision for people with learning disabilities. They also highlight the important role social care workers could undertake as effective health advocates.

Michelle, senior support worker to Graham, claimed Graham had been treated differently in hospital because of his learning disability and if he had

been able to speak for himself this ***prejudice and discrimination*** would not have occurred.

Michelle's statement echoes a survey conducted by Mencap (2010) highlighting that the NHS discriminates against people with a learning disability. An opinion poll of 1000 NHS staff identified almost half (45%) of doctors and a third of nurses (33%) admitted they had personally witnessed a patient with a learning disability being treated with neglect or a lack of dignity and 39% of doctors and 34% of nurses stated that people with learning disabilities are discriminated against in the NHS. Under both the Human Rights Act (1988), which incorporated the European Convention on Human Rights in UK law in 2000, and the Equality Act (2010) reasonable adjustments must be made by those providing services, including health services, to ensure everyone has equal access to services. From Michelle's comments and the findings of the Mencap (2010) report above, it appears serious breaches of these laws are being committed. This again highlights the requirement for people with learning disabilities to have access to effective health advocates and demonstrates the need for social care workers to be adequately trained and acknowledged within this increasing dimension of their work.

Several participants ***underestimated the tenants'*** ability to understand their illness, symptoms, diagnosis and/or their prognosis. Participants' assumptions meant tenants were sometimes denied the opportunity to make decisions concerning their health and treatment. (See page 268 for further

discussion on decision-making). In this study, the majority of tenants were denied the opportunity to make their own decisions concerning their health and treatment, with the majority of participants making assumptions and decisions on their behalf. These findings echo those of the confidential inquiry into the premature deaths of people with learning disabilities (Heslop et al 2013) and again demonstrate staff's lack of awareness of the Mental Capacity Act (2005).

Two participants commented on how they believed the tenant they supported had a particularly **high pain threshold**. Whilst these two tenants may well have had a high pain threshold, it cannot be assumed that people with learning disabilities generally have a high pain threshold. This issue is well documented in the literature (Beacroft and Dodd 2009, 2010, Turk et al 2011, Findlay et al 2013). Whilst it is recognised that people with learning disabilities may not display pain in the typical way, Beacroft and Dodd's (2009) study reported one third of staff interviewed still believed people with learning disabilities have a higher pain threshold than that of the general population. This study also reported that pain is not always recognised or managed well in residential settings, with tenants sometimes not being given medication and/or not in a timely manner. In this study, two participants assumed their tenant had a high pain threshold. In reality they were unsure whether the tenant was in pain and unclear whether it was part of their role to administer medication, particularly for cancer. Again, this demonstrates confusion surrounding their role.

All participants accessed cancer information from a variety of sources. These included from their own personal experiences, leaflets from the team managers and discussions with other team members, the district nurses and GPs. There was no co-ordinated procedure to access cancer information or support, either by each project or by the service organisations as a whole. Many participants claimed their **information and support needs** were not met. The majority reported they had not seen or been in contact with Macmillan or any specialised cancer staff although some participants reported they would have welcomed the opportunity:-

I think from a team point of view, if down the line we'd have been told about Graham, we could have had a team meeting where everyone could have given his or her opinions. We could have had a Macmillan nurse in to talk to the team as a whole, to say 'look this is what we do, this is what you're facing', but there was none of that. Nothing at all. No information given (Michelle, senior support worker for Graham).

Despite the guidelines published by the National Institute for Clinical Excellence (2004) stipulating that high quality cancer information should be available to all patients (including those with disabilities) and carers, the information needs of cancer patients are not being met (Voogt et al 2005, Mallinger et al 2005, Macmillan 2012) Whilst some might argue that individuals can be overwhelmed with information, the quantity and quality of information available appears to be largely dependent on where treatment is provided and the staff knowledge within that setting.

Other concerns exist surrounding the dissemination of cancer information to people with learning disabilities. For example, cancer professionals may direct information at the support worker/carer (Jones et al 2007). As many support workers/carers lack awareness surrounding the Mental Capacity Act (2005) they may decide to withhold this information, based on their own assumptions (Tuffrey-Wijne and Bernal 2003, Jones et al 2007, O'Regan and Drummond 2008). In the study conducted by McEnhill (2004) findings highlighted that social care workers did not have the experience or adequate training to deliver cancer information and as previously discussed on page 236, may not even be aware it constitutes part of their role.

Several participants explained accessing advice and/or reassurance concerning administering drugs through a syringe driver was problematic. Betty suggested there should be a main contact to provide this advice:-

The thing is, all right the lady has got the syringe driver, you have given Oramorph, all that you can give but sometimes you need that reassurance that you are doing the right thing and thinking what's my next option? But it's the urgency of it. Perhaps there should be like a contact. In an ideal world there should be a cancer support line that you could ring them up and say 'this is my situation now, what do I need to do,' isn't it? (Betty, manager to the team supporting Joan).

There is a telephone information service providing cancer information; unfortunately at that time, Betty was unaware of it. Macmillan, Tenovus and the Palliative Care of People with Learning Disabilities Network offer such services. This lack of awareness concerning the availability of existing support demonstrates how vulnerable staff are when having to respond to serious and potentially dangerous situations. It also demonstrates how vulnerable the tenants are to receiving poor quality care.

Participants reported information received from healthcare staff was sometimes inconsistent and created further tensions between social care staff and healthcare staff. Lorna discussed how different district nurses gave differing advice, sometimes contradictory. This resulted in social care staff feeling confused about what to do and how to do it and vulnerable to being admonished by healthcare staff for their actions:-

All these district nurses are different characters and they all say different things. They say 'put iodine on the wounds', 'no don't do that', they are contradictory. So they might come in and say 'what have you done that for?' You know and it upsets staff because they are trying their best but they could be quite belittling (Lorna, support worker for Joyce).

Many participants gained information and support from their colleagues, particularly those with healthcare experience. Mary had been a nursing assistant in a nursing home for over ten years prior to her social care role

and provided her colleagues with invaluable information and support during Graham's illness and subsequent death: -

Some of the staff were breaking down and that shocked me. We should have had a meeting stating what was involved. I knew what was involved because he (Graham) was nursed in bed. Staff would say to me, 'well how do you do that?' I had a few people shadowing me, and I showed them how to change him in the bed, how to change the bed, how to wash his hair in bed. But it shouldn't have been me showing, we should have had a meeting (Mary, support worker for Graham).

Mary's comments illustrate how under-equipped her colleagues were to provide palliative care to Graham. Fortunately for the support staff involved with Graham, and purely down to luck rather than planning, Mary had prior experience of providing palliative care. This experience enabled her to direct and teach her colleagues what needed to be done. The majority of staff supporting Graham had no prior experience of providing palliative care although it appears the service organisation expected Graham's social care workers to provide this type of support as part of their usual role.

The issues surrounding social care staff providing palliative care to tenants is well documented (Brown et al 2003, Tuffrey-Wijne et al 2007, Reddall 2010, Ryan et al 2011, Wiese et al 2012, Todd 2013) (see page 254 for further discussion on palliative care). Despite this body of knowledge and

subsequent recommendations for good practice, the service organisations involved in this study had no formal policies, procedures or guidelines in place to support participants providing palliative care to tenants.

Two participants explained how they were not informed of, or prepared for, the procedures following a tenant's death. Both Bob and Mary, supporting Graham, were shocked and frightened when the GP refused to sign Graham's death certificate and called the police. When the police arrived they requested Bob and Mary complete a statement. As Graham had never formally received a diagnosis, the GP was unable to sign the death certificate and so followed procedure by calling the police who in turn followed their procedure by asking those present at Graham's death to provide a statement. Having both been with Graham when he died, just an hour or so beforehand, Bob and Mary were unprepared for what followed and both expressed how frightened and anxious they had become following Graham's death: -

Bob: *The night he died both me and Mary were in his room with him. He passed away quite peacefully. Then the GP came and of course he wouldn't sign the death certificate.*

TC: *Why?*

Bob: *Because they knew he had the cancer but they didn't know the actual cause of death. Right. So the GP did his examination and then the bloody police came.*

TC: *Really?*

Bob: *Yeah and well me and Mary had visions they came to check his body (for foul play).*

TC: *That must have been quite frightening?*

Bob: *It was because I had to make a statement to the police, which no one had mentioned.*

TC: *So you weren't prepared for it?*

Bob: *No. Totally scared. Well he had just died in front our eyes. So that always sticks in my mind.*

Participants' feeling unprepared was not restricted to Bob and Mary's experiences. One participant was angry the diagnosis had taken so long to obtain and claimed this had restricted staff's ability to prepare themselves for the tenant's illness and subsequent death: -

So we did get really angry and we did get really frustrated because I think if we had been given the information much sooner, we could have all prepared ourselves. There was no training. We are not healthcare assistants, that is not our role (Michelle, senior support worker for Graham).

4.4. Internal Barriers

Fifteen initial codes combine to create this focused code and relate directly to the internal barriers participants encountered when supporting a tenant with cancer. Internal barriers are largely connected to the internal structures of the organisation such as staffing levels, policies and procedures. The role ambiguity staff appear to have experienced also contributed to these internal barriers. For example, the majority of staff argued they were employed as social care workers and their role was to support the tenant in their daily tasks and routines, promoting independence and autonomy. They argued they were not healthcare workers providing healthcare support and palliative care for which they had received no (or minimal) training and for which they had no or minimal experience.

During this study the majority of participants described how their role as a social care worker changed as a direct result of supporting a tenant with cancer. They reported how they had to undertake healthcare tasks, which they had no experience of and were not trained to provide. Some participants argued this **role change** left them and the tenant at risk and were seriously concerned they would make a mistake. Whilst there is some cross over between role change and role ambiguity, role change demonstrates how some participants perceived their role to actually change from one of support worker to healthcare worker. In contrast role ambiguity

demonstrates participants' confusion and lack of clarity surrounding the expectations of their role.

Lorna, support worker to both Ben and Joyce, reported that as she took on these extra healthcare tasks she felt vulnerable, particularly as there was an increasing focus on risk assessment and health and safety issues within the service organisation: -

As the cancer progressed and then ... it was quite quick actually but the morphine was... its things like that then all of a sudden you have to administer it orally. Ben had it orally. But you are so vulnerable. It is your job, but if you are doing something wrong and it ... sometimes you don't want that, you want to be solely there to support them and not be thinking oh gosh have I done this right, should I do it? (Lorna, support worker to Ben and Joyce).

This expectation to undertake healthcare tasks such as administering cancer medication, without having received formal training created a real sense of role change for Lorna who explained a recent event where she reported being placed in a vulnerable position and potentially felt at risk of losing her job: -

It shows how vulnerable you are if a catheter is blocked well of course they start going into trauma and err... I think it was the black Friday³ when the ambulances were out and we were told we were not to do any procedures because we are not trained and in the end we had to do a flush because it was either that, because he was getting very traumatised because we don't know what would happen at that stage, and again.... I put my job on the line. The on call health professional gave it the go ahead but there could have been a backlash on it if that flush had gone wrong and you ... and then again you've got, you are in a real predicament. If I don't I am damned, if I do... you know. It's a difficult place to be (Lorna, support worker to Ben and Joyce).

As previously mentioned, Mary (support worker to Graham) had recently left a nursing home as a nursing support worker to become a social care worker. She had left her previous employers in an attempt to change her daily duties from undertaking healthcare tasks to undertaking social care tasks. As a social care worker supporting Graham, when he became ill, ironically she was not only expected to undertake healthcare tasks but additionally, teach and support other members of social care staff to also undertake healthcare tasks: -

³ Black Friday, is the last working Friday before the Christmas Bank Holidays when the majority of staff parties take place. All medical services are put on alert, as there is usually an exceptionally high demand for emergency medical treatment.

I had experiences before Graham because I worked in a nursing home, so I had experiences of different illnesses and so, you know I was aware. I wasn't shocked or distraught like the others because I had six years. It was a shock because I went from a nursing home to a support worker and I had seen all that and I didn't think I would see it so quick (laughter)
(Mary, support worker to Graham).

Bob, support worker to Graham, had expressed his reservations concerning supporting Graham with cancer and when he voiced his concerns, the team manager explained she had taken it for granted the support workers would want to support Graham and had not considered that the staff would **have the choice to opt out** of providing support to Graham.

Bob's primary concern seems to relate to his ability to provide Graham with the support he needed. Not having had any healthcare training and having had no prior healthcare experience, Bob had no idea what he would be expected to do, whether he would be capable of doing it and whether his lack of knowledge and experience in this area would have a negative impact on Graham. These appear to be reasonable concerns. Perhaps what seems unreasonable is for the manager of the team supporting Graham to automatically assume Graham's social care workers would provide palliative care without prior discussion with them. Bob felt it was important for all staff to have an opportunity to find out what was expected of them, ask questions and request relevant training if they required it.

The manager explained she had taken for granted the social care workers would want to support Graham. This assumption appears to be based on the emotional nature of the relationships shared between Graham and his support staff, despite service organisations preferring to ignore the emotional dimension of the support workers' role (Hall and Hall 2002). Ironically, it appears it is precisely this emotional dimension service organisations seem now to be relying on when taking for granted support workers' willingness to support the tenant through illness and possibly death. Notwithstanding, whilst hesitant at the beginning, Bob was pleased he had been able to provide support to Graham through his illness:-

I enjoyed working with Graham, he was a real character and eventually when he did die it was me and Mary that was with him. In the beginning I queried with Michelle, look how hard is this going to get, because at the end of the day we are support workers, we are not health carers and people don't differentiate between that but I did say 'are we going to be able to cope as a team with it?' And she said 'well I never really thought of that' she said 'I just assumed that when the time come we'd have him home.' But I'm glad we did now because I think he had a far better... because he was two staff to one in the end so you know (Bob, support worker to Graham).

Michelle also argued their role changed as a result of supporting Graham with cancer and this had become an issue for some staff:-

- Michelle: *I think initially there were some feelings that Graham shouldn't be at home, that staff didn't have the experience to deal with it.*
- TC: *Or the training?*
- Michelle: *Or the training, there was no training.*
- TC: *Because there is no healthcare training required?*
- Michelle: *No, we are not healthcare assistants, that's not our role.*
- TC: *So it's quite a big responsibility? It must have been really frightening?*
- Michelle: *It was very frightening not knowing what to expect. I did speak to the GP and asked him, 'what is going to happen?' So we had Graham there very, very ill. We knew he was terminally ill but none of us knew what stages we would be faced with. I think that was quite hard.*

Again the majority of participants reported they had not had the opportunity to discuss this unexpected and new dimension of their role. They felt they had not been given a choice over whether they wanted to support the tenant with cancer, or been offered or given any training to equip them to undertake these new tasks.

Two participants argued it was up to those who may have had an issue to come forward and voice their concerns. They stated staff would have been given the option by the service organisation to move to another project. For example, Tanya, one of the managers of the team supporting Joyce, stated

that staff unable or unprepared to support a tenant with cancer would have the option to move projects or if necessary receive counselling:-

Yes and if you feel that you can't go to the manager and tell them, 'I just can't cope with that' and then they might suggest you have counselling or whatever you know or fit you into another role (Tanya, manager of the team supporting Joyce).

These comments appear to give social care workers a choice. In reality, staff may find it difficult to admit they were not coping, not least because it would challenge aspects of their role identity and their need to be perceived as strong. Additionally, the request to be moved to another project and work alongside unfamiliar colleagues may present a significant upheaval.

Over half of the participants reported their concerns and fear of **not being able to cope** with the unknown challenges of supporting a tenant with cancer. Bob, support worker to Graham, was not only concerned for himself but also for Graham and the rest of the team: -

How bad it was going to get for him and how was he going to cope with it. Having not only a learning difficulty, he was deaf and he couldn't talk like. So how frustrating it was going to be for him and the team. You know how were we going to cope with it because like, it was a new thing to us (Bob, support worker to Graham).

Two participants suggested tenants could detect their fear. They reported how tenants could be extremely intuitive and as they knew the social care workers very well, they were able to ***pick up on body language***, read their mood and/or emotional state. These interactions are symbolic of the closeness of the relationships social care workers and tenants share.

Within the literature, this is an underexplored area, but one that is worthy of greater attention. This is particularly pertinent for social care workers of tenants who are ill and/or dying and those that have supported tenants for many years. Certainly in this study, the majority of participants went to great lengths to hide their reactions and emotions from the tenants, for fear of upsetting them or in some cases alerting them that something was seriously wrong. Arguably this helps to demonstrate the importance of truth-telling in these situations, not only for the tenant to be able to make an informed choice concerning their future treatment and care but also for the social care worker to openly come to terms with events. Having to hide emotions and regulate behaviour is not always effective as the tenant may well be aware something is wrong and by not knowing the truth, may worry further and unnecessarily. Repressing emotions may also affect the emotional wellbeing of the social care workers. This internal barrier involving staff having to disguise their emotions concerning the tenant's illness for fear of their tenant picking up on their body language demonstrates a lack of clarity surrounding their role and their responsibilities in this regard. Furthermore, not disclosing the tenant's diagnosis and prognosis may have significant repercussions on both the tenant and the social care worker.

Insufficient **staffing levels** created another internal barrier and may have increased staff experiences of role ambiguity as their time to undertake new challenges was placed under further constraints. Adequate staffing levels were important to the majority of participants. This was particularly so when the tenant needed to attend the doctor and/or hospital appointments. As the tenant's condition deteriorated a greater degree of staff attention was required, which placed further pressure on staffing levels. Bob stated that during Graham's illness, staffing levels were always tight but, as a team, they worked together over and above their contract hours to ensure Graham was adequately supported:-

You need to make sure that you've got staff for him you know that person that has cancer and you need to make sure which fair play the team did because like, we all done over and above our work. You know we've got contact hours you see. We were always pressed though you know what I mean? (Bob, support worker to Graham).

Three participants reported a **lack of organisational support**. This was particularly so with regard to staffing levels during the tenant's illness and after the tenant had died. Participants argued the organisation was initially too slow to increase staffing levels and too quick to reduce them once the tenant had died. Michelle reported the team had provided support during Graham's illness and eventual death but no help was offered to staff by the service organisation after Graham's death. Similarly there had been no

acknowledgement by the service organisation of the extra work and commitment they had provided: -

TC: *Who or what has been the most helpful to you during this period?*

Michelle: *(Long pause). The staff team. Those of us in the staff team that went through it because we still talk about it now. As far as an organisational perspective, there was no help offered, nothing.*

TC: *No counselling or anything afterwards?*

Michelle: *Well, you're always told there's Sterling counsellors available, but nothing. We did have a letter sent to the staff team thanking us from the Chief Executive but I did feel really cross at that time that nobody came out to a team meeting and said thank you and well done.*

TC: *So you felt really taken for granted?*

Michelle: *Mmm. Although it was something we wouldn't have changed, we would have done that for Graham, it's not the point and it was so over and above our role.*

TC: *You felt the least they could have done was acknowledge that?*

Michelle: *Yes.*

TC: *Would it have made you feel any better?*

Michelle: *That team had done so much for Graham and so much was expected of them that I do think the organisation*

should have given them acknowledgement for that
(Michelle, senior support worker to Graham).

There is limited research exploring the attitudes of service organisations towards their staff and if, and how, they reward staff for displays of extraordinary commitment.

Participants commented on how decisions made by management sometimes made it difficult for them to do their jobs properly. For example, May and Lorraine, support workers for Joyce, both stated they **were unable to do their jobs properly** when management and others decided Joyce's cancer diagnosis should be restricted to her key workers only.

Having the correct information concerning the tenant's condition was important to staff. Seven participants discussed how they sometimes became the tenant's voice and were responsible for challenging individuals and/or issues in their tenants' best interests. It is interesting to note that some participants did consider advocacy as part of their role, whilst others did not. It is also interesting that participants seemed to select the issues they were prepared to provide advocacy on. This *ad hoc* approach demonstrates the confusion some participants felt surrounding what aspects, if any, of advocacy they considered to be part of their role. For example, both Anna and Janet, senior support worker and manager of the team supporting Jim, stated if they had not pushed at the hospital for Jim when he was admitted, then no one else would have: -

If you don't push for them, then nobody else will, because they haven't got the ability to fight (Anna, senior support worker to Jim).

Jim couldn't communicate that you know, we were his voice (Janet, manager of the team supporting Jim).

Three participants stated that at times they felt they were in a '**Catch 22**' situation. On the one hand their role required them to support the tenant first and on the other, this commitment clashed with their other responsibilities. For example, Janet, manager of the team supporting Jim, wanted to express her frustration and anger at how the GP refused to acknowledge there was something wrong with Jim. At the same time she felt as an employee of Sterling she was required to behave professionally: -

Yes, and you are also caught as well because at the end of the day I am also the representative of the company I work for (Janet, manager of the team supporting Graham).

For one participant having what she described as a **big gap** in service provision placed her in a difficult situation with her team. Rachel, manager of the team supporting Neil, could not find a permanent place in a hospice or nursing home for Neil and was providing target support at his home. To get the staffing hours to provide support was problematic for Rachel. Whilst she wanted to ensure Neil received the support he needed, she also had to

explain to the team there were staffing restrictions on what she could realistically provide due to financial constraints determined by the service organisation:-

The staff will say to me, 'well why has he got to go to a care home? Why can't we have hours for him?' And I am trying to explain to them the reasons why he can't and it is frustrating. They don't realise how much you work tirelessly sometimes. They don't understand the confines because all they want is the best for him isn't it? (Rachel, manager to the team supporting Neil).

The majority of participants (n=11) commented on their experiences of providing **palliative care** to the tenants (see page 223 for further discussion on palliative care). These participants stated they were glad they had had the opportunity to provide palliative care particularly as the terminally ill tenants in this study (n=5), wanted to die at home. Three participants commented on how it had been a privilege to provide palliative care to their tenants.

Many people with learning disabilities have had poor experiences of medical environments as a result of their exposure to institutions or hospitals earlier in their lives (see page 210 for further information). These experiences have resulted in some people with learning disabilities preferring to die at home rather than in a hospital or hospice. Whilst many people would prefer to die at home, this request can be more difficult to accommodate within the

general population as the majority of people live in their own homes, independently and without support. As people with learning disabilities already live in supported accommodation with allocated social care workers, the request to die at home may be easier to facilitate.

Mary, support worker to Graham, who had previously worked in a nursing home and who had prior palliative care experience explained how proud she was to have had the opportunity to support Graham through to his death:-

I didn't want him to be on his own. So when he did pass away I did shed a little tear and because then he was at peace, you know what I mean? I was so proud that I had done from the beginning and had seen it right through to the end (Mary, support worker to Graham).

Through participants' dedication, commitment, support from the district nurses, and each other, they facilitated several of the tenants desire to die at home.

For the majority of participants supporting the tenant **at the end** of their lives was extremely difficult as Anna, senior support worker to Jim highlighted:-

And then towards the end when he was really, really ill then it was hard supporting him. It was really hard supporting him (Anna, senior support worker to Jim).

Main challenges included fear of the unknown, learning new tasks such as changing a bed with the tenant in it, washing hair in bed and liaising with healthcare staff. Accessing information concerning cancer, managing pain, managing and supporting the other tenants, working longer hours both paid and unpaid and managing their own physical and emotional exhaustion also proved challenging. Remaining positive around the tenant, wondering whether they (social care worker) were doing or had done enough for the tenant, watching someone they had known and cared for deteriorate and co-ordinating with the tenant's family also proved difficult. Todd's (2013) recent study exploring 22 staff experiences of death and dying in five different service organisations, reports those involved with tenants who experienced a prolonged and/or difficult dying period were sometimes forced to withdraw, because of their feelings of fear, isolation and a perceived lack of support (Todd 2013).

Nine participants discussed how the tenant's illness and/or subsequent death had **impacted on the other tenants** in the house. This issue is largely ignored in the literature surrounding people with learning disabilities, cancer and death. The reaction of other tenants created a further internal barrier for staff to overcome. Helping other tenants to understand what was happening to the tenant with cancer placed an extra emotional burden on participants.

Participants were confused surrounding their role in dealing with other tenants' reactions in this regard. They also felt under-equipped to provide the support needed. In some cases, where other tenants knew something was seriously wrong, participants had to find the right words to explain what was happening. Participants claimed tenants' reactions varied greatly from a total lack of comprehension to a serious change in behaviour. Participants became constantly aware of the other tenants' reactions to the tenant with cancer and stated they had tried to keep things as normal as possible for them.

Anna explained how the other tenants were not told how seriously ill Jim was and how they reacted at Jim's funeral:

He knew but obviously we couldn't tell him how bad he was. The funeral was hard. We were facing the coffin and the other service user was by the side of me and he did laugh, but he was sobbing. I thought come on, it's all right. He was upset. I think because we tried to keep things normal and we had allowed him to talk about it at any time, he kept saying Jim this and Jim that and I said 'I know Paul', which was good. We kept Jim's memory going to help him deal with it, which worked (Anna, senior support worker to Jim).

Participants wanted to protect tenants from the anxiety sometimes associated with knowing the truth and these decisions were based on staff

attitudes about truth-telling and their perceptions of the needs of the tenants. None seemed to consider disclosing the tenants' prognosis as an opportunity to additionally prepare the other tenants for their friends' death.

Several participants highlighted their involvement in organising the tenants' **funeral plans**. Some tenants had helped to organise their own funerals by purchasing a funeral plan, whilst others were happy to leave the arrangements for the staff to organise. One of Jim's relatives asked the staff to organise Jim's funeral:-

She wanted the manager to make them so the manager sorted it all out with her there like, but she wanted me and the manager and the other service user in the car with her and this other member of staff because we were the main ones that supported him through the appointments and keeping her informed so she wanted us in the car with her. So.... but she wanted us to do it. Which was fine. We didn't have a problem with that
(Anna, senior support worker to Jim).

A recent study carried out by Forrester-Jones (2013) explored the views of older people with and without learning disabilities concerning funerals. It investigated how practitioners responded to funerals, identified inconsistent responses by services in organising and funding a tenant's funeral and found limited involvement of the tenant in planning their funeral. It also agreed with

the findings of Todd and Read (2010) that people with learning disabilities want to discuss and participate in this topic.

Two participants from the same housing project described how Graham's family removed his personal belongings from his room almost immediately after his death. A new tenant was then moved in. This coincided with the service organisation moving the staff team onto other projects. These actions left participants feeling isolated and adrift. As Bob explains, they were unhappy being forced to ***move on too quickly*** after Graham's death:-

As soon as Graham died, they shipped the team out, so it completely destroyed the team. The hours are not there anymore so they have to go to other projects. But it is quite heartless. We could have done with the support from each other when Graham passed. It was just so shocking. But at the end of the day that's what it comes down to is money (Bob, support worker to Graham).

Whilst social care workers are committed to providing palliative care for tenants, perceive it as a privilege and gain personal achievement when they facilitate a 'good' death for a tenant (Ryan et al 2011, Todd 2013) they also experience the personal cost of providing such support. Feelings of guilt, fear, isolation and inadequacy contribute to their feelings of grief. A recent study conducted by Ryan et al (2011) exploring paid social care workers' perspectives of end of life care for people with learning disabilities highlighted

the need for service organisations to be sensitive and supportive to the distress staff experience during periods of bereavement. Whilst staff acknowledge the ongoing demand for services, the transition to moving a new tenant in to occupy the deceased person's room should allow time for staff and tenants to grieve and be managed in a respectful way. Staff felt there should be a minimum of four weeks before reallocating rooms (Ryan et al 2011).

4.5. External barriers

This focused code consists of four initial codes. These represent the external barriers that negatively impacted on social care staff. These barriers contributed to the confusion and lack of clarity surrounding their role.

All of the tenants suffering with cancer had relatives. Some family members visited regularly but the majority did not and lived a significant distance away. For example, Graham's family lived in the Midlands. Whilst social care staff are encouraged by the service organisations to involve the family wherever possible in the tenant's life, the majority of the participants found the external ***family involvement*** challenging. Social care workers' close relationships with their tenants may feel undermined by the symbolism attached to being a relative, making their interaction complex. Where tenants and participants had very minimal contact with the family prior to the tenant's illness, the

external '*interference*' from family members sometimes hindered the tenants and participants daily routines. Participants had to take family members feelings into consideration and facilitate and negotiate their requests for involvement in the tenant's illness. Having to '*share*' the tenant and responsibility relating to the tenant's illness was at times very difficult for some participants and led to confusion surrounding what was their responsibility and what was the family's responsibility.

Kelly, key worker to Joyce, and support worker to Ben, found Ben's family particularly difficult to manage. Ben had three adult daughters who visited infrequently. When Ben became ill they visited far more frequently. Whilst Kelly was able to identify how and why she found their presence difficult, during the interview she did not seem to have considered why Ben's daughters behaved the way they did around and towards Ben: -

The hardest thing I found was the family. When I was caring for Ben, he had three daughters who came infrequently. I had known him for fifteen years, but he was like an uncle figure. They (his daughters) came into his life whilst he was dying and I have seen this man everyday for the last fifteen years and I know him really well and he is your father, he is not mine. They literally spoke to us like we had never known him. It was bordering on insulting and when we would go to the hospital appointments they would just keep giving him fags and he was on morphine and he was throwing up and he was grey and looked like he was going to die just there and then (Kelly, key worker to Joyce and support worker to Ben).

As previously stated, whilst service organisations encourage support staff to involve the tenant's family, organisations do not acknowledge the close relationships staff sometimes share with their tenants and how family involvement can impact on these relationships, particularly when a tenant becomes ill. A recent study carried out by Wiese et al (2012) at the University of Sydney, highlights the complexity of relationships between the partners involved, such as family, paid carers and friends and the care issues associated with dying. Wiese et al's (2012) study was carried out using four focus groups and 23 individual interviews and also highlights how social care workers had to sometimes manage several issues at once whilst simultaneously being mindful of the partners involved. In a qualitative study conducted by Furniss et al (2011) involving collecting data through 13 semi-structured interviews exploring service provision, the need for services to respect relatives and family carers views and offer them the opportunity to access information and become proactively involved in the tenants illness was highlighted. Although it should be noted this study only focused on the views of people who care for adults with Down's syndrome and dementia and involved participants who had either exceptionally positive or negative experiences of caring. Differing ethical values and opinions between family and staff require skilful negotiation (Kirsch 2009) and clear ethical frameworks to assist decision-making are vital (Flynn et al 2009).

Despite participants incorrectly assuming being next of kin provides access to vital medical information, some participants reported they could not access this information because the **next of kin** were not available. Michelle, senior

support worker to Graham, argued if she had told the hospital she was Graham's daughter, she could have accessed the information she needed to support Graham properly.

This highlights the lack of knowledge support workers have concerning the rights of the next of kin to access their relatives' medical information. CIPOLD (Heslop et al 2013) reported 27% of the people in their study had no contact with family members or any known family members. They relied on social care workers for support who had limited comprehension of the Mental Capacity Act (2005). CIPOLD (Heslop et al 2013) also identified that many service organisations sometimes had little or no previous medical or personal histories of the people they were supporting and this also had serious implications for those tenants who became ill.

Several participants described problems with ***inter-agency working***. These problems included issues surrounding nursing staff in hospitals, community/district nurses, GPs, and/or hospital consultant staff. The key problems seemed to involve poor communication (see page 232 for further information on communication with healthcare staff), a lack of understanding around learning disabilities (see page 233 for further information on prejudice and discrimination), a lack of understanding surrounding the role of a social care worker (see page 228 for further information on a lack of respect for social care staff), and a lack of understanding concerning the relationship between the social care worker and the tenant (see page 227 for further information on the lack of understanding by healthcare staff). Despite these

issues, several participants reported positive incidents and events involving a variety of staff (see page 225 for further information on positive working practices). Participants appeared generally confused concerning their role in rectifying these issues and in improving joint working practices.

All participants reported **agency staff** (workers who are engaged through an employment agency and supplied to an employer on a temporary basis), were not employed to support the tenant during their illness. Where staff shortages did arise, staff were recruited from other projects within the organisation to cover shifts. All participants explained how they would have objected and/or not have agreed to the use of agency workers to support the tenant during their illness. The majority of participants perceived the use of agency staff in these circumstances as a dereliction of their duties, despite there being no clear definition of what their duties actually entailed. Interestingly, on the one hand this attitude compounded aspects of their role identity by demonstrating their commitment, and yet on the other it demonstrated that despite experiencing role ambiguity, participants remained completely committed to providing the support their tenant required.

4.6. Communication barriers

Eight initial codes combine to create this focused code. These relate to how communication barriers created further confusion surrounding the

expectations and responsibilities of their social care roles. They also highlight how this lack of clarity concerning providing effective communication can be detrimental to their own wellbeing and their tenants.

One of the main communication barriers existed between social care workers and healthcare staff. Twelve of 14 participants experienced problems ***communicating with healthcare staff***. Communication barriers existed across a range of medical and healthcare staff including GPs, nurses, district nurses, and hospital consultants. Issues included obtaining a diagnosis and prognosis, treatment options and palliative care. In particular the communication barriers between social care staff and healthcare staff had a significant impact on obtaining a timely, clear and concise diagnosis and prognosis of the tenant's illness. This in turn sometimes confused staff, who relayed incorrect information not only to each other but also the tenant. For example, Kelly was told Joyce needed a mastectomy although during the interview Kelly and other participants supporting Joyce referred to Joyce's cancer as terminal. Whilst breast cancer can be terminal and a mastectomy may still be offered, in Joyce's case, this had not yet been determined:-

We went back and fed to the staff... Louise the counsellor there (hospital) said 'I can come to the meeting' and we should have done that straight away. She is still yet to come but we should have done that straight away because we were relaying information second hand and we came back and said you know Joyce's prognosis is not good. We must have said

terminal along the line, that it will kill her, I don't think we did but any way it all became about terminal cancer (Kelly, key worker to Joyce).

Kelly's comments also highlight internal communication barriers between social care staff. How information is shared within staff teams, particularly between key workers and support workers is vital in ensuring support is co-ordinated and the team are collaboratively striving to meet all the needs of the tenant. Staff seemed unprepared for the responsibility of sharing a tenant's diagnosis and prognosis with colleagues and confused about their role in sharing it.

To help overcome the communication barriers between support staff and healthcare staff, some participants ***involved a third party*** such as a speech and language therapist and/or a diabetic nurse. For example, Anna had made repeated visits to Jim's GP and raised her concerns regarding his deteriorating health. On one occasion Jim presented with a lump on his abdomen and Anna was told it was nothing to worry about and was probably a hernia. The GP also told Anna Jim's continuing weight loss was good as he needed to lose weight anyway and it was probably just a series of stomach bugs. The GP finally referred Jim for medical investigations when his speech and language therapist expressed her concern at his poor physical condition following her annual review with him. One afternoon whilst Jim was waiting for his referral, he started to vomit faeces. At the same time Anna was discussing another tenant with one of the community nurses on

the telephone and when Anna explained what was happening with Jim, she was told by the community nurse to get Jim to the hospital immediately.

Anna's experiences reveal how involving a third party, particularly a member of healthcare staff, gave her concerns greater credibility. This demonstrates a power differential between support staff and healthcare staff. This imbalance can jeopardise a tenant's health and treatment pathway. CIPOLD (Heslop et al 2013) report that over one third of research participants experienced problems with receiving a diagnosis. The most common problem was a reluctance to carry out investigations. One quarter of the cases reviewed found that healthcare staff did not take the family and/or the paid social care workers concerns seriously.

For some participants, involvement by a third party provided some reassurance. **Staff reassurance** enabled participants to feel they were justified in their concerns surrounding their tenant's deteriorating health. By having another member of staff involved, particularly healthcare staff, participants gained increased confidence when dealing with medical professionals such as GPs. This suggests social care workers are under-equipped to communicate effectively with medical professionals on behalf of their tenants.

The majority of participants reported a variety of issues surrounding **truth-telling and full disclosure** of the cancer diagnosis to the tenant (see page

249 for further discussion on truth-telling). Three of the six tenants with cancer were informed they had cancer. Some participants communicated the diagnosis in stages to allow the tenant to come to terms with their condition gradually.

Throughout this study when participants were asked to make decisions relating to the tenant's treatment and/or medication, participants approached this **decision-making** based on what they personally perceived to be in the best interests of the tenant (see page 204 for further discussion on the Mental Capacity Act (2005)).

None of the tenants in this study were offered counselling. All participants reported they were offered **staff counselling** by the service organisation. Although none of the participants received counselling during or after the tenant's illness and/or subsequent death. Some participants were worried that by asking for counselling, colleagues and the service organisation may have viewed them as weak and unable to cope. As previously discussed in Chapter 4, page 199 being strong and coping were important characteristics of the social care worker role identity. For example, Lorna argued that whilst support was inadequate, she would not ask for counselling for fear of other staff members finding out: -

I have got to be strong for them (the tenant) and I have got to do my job and then after (when the tenant dies), there is nothing, that's where the

support stops. I wouldn't know where to go with it. You don't want to go through the manager if there is an issue. You would feel you were the weakest one out of your team. I would worry about other team members knowing I was receiving counselling. I will go home and break down and cry in front of my partner and be quite low for a while, a bit snappy (Lorna, support worker to Ben and Joyce).

In contrast, Michelle, senior support worker to Graham, was under the impression it was the responsibility of the service organisation/counsellors to approach her and offer her counselling. She did not consider it was part of her role to approach them.

Anna, senior support worker to Jim, argued **counselling services for other tenants** should be available when tenants are coming to terms with the illness and/or subsequent death of a fellow tenant, friend or even family member. This seems to indicate that support workers are being expected to provide bereavement support to tenants, which they may feel under-equipped to provide and confused concerning their role in this.

All participants stated **communication is vital** in managing, coping and surviving a tenant's illness and/or subsequent death but also the confusion, lack of clarity and ultimately the role ambiguity participants experienced as a result of supporting a tenant with cancer.

4.7. A reflective account of role ambiguity

As I collected and analysed the data it was clear to me that staff were experiencing role ambiguity. There was a lack of clarity surrounding their roles and they were confused about what they should or should not be doing. I sometimes felt shocked at participants' accounts of tenant's experiences. For example I was shocked to learn of the extent of Jims' deteriorating condition before anyone would listen and take seriously her concerns. As role ambiguity was the result of my interpretation of the data, and at no point did participants perceive their confusion or lack of clarity concerning their role as role ambiguity, it was particularly challenging for me to convince my supervision team of this role ambiguity and even more challenging to demonstrate it through my writing. During this process I gained valuable insight into my lack of ability to articulate my interpretations clearly and in a way that facilitated instant understanding. To ensure the concept of, and connections to, role ambiguity became clear and concise, repeated revisions of this text have been necessary. As a result, my ability to write more clearly and concisely has improved.

4.8. Summary

This chapter reported on the theoretical category of staff role ambiguity. Role ambiguity was explored in terms of the different barriers participants

experienced when a tenant became ill. In particular, participants felt they were under-equipped to provide some of these healthcare tasks and confused concerning their responsibilities in providing them. For example, confusion existed surrounding who was responsible for delivering cancer information to the tenant.

Findings also revealed a lack of awareness by social care workers concerning cancer, and a lack of awareness by healthcare staff concerning the role of social care workers and their relationships with their tenants. This sometimes resulted in imbalances of power and poor relations between support staff and healthcare staff. Many participants were confused concerning their role within the healthcare environment and felt undervalued, which compromised their ability to be effective health advocates.

The palliative care information needs of all participants largely remained unmet and at times left staff confused and fearful concerning their ability to meet their tenants' palliative care needs. Service organisations relied on the close relationships staff shared with their tenants and took for granted that participants would provide this support. Despite this, service organisations were also, at times, insensitive to the close relationships staff and tenants enjoyed, particularly when a tenant died.

Poor communication and a lack of awareness surrounding the Mental Capacity Act (2005) denied some tenants the opportunity to make or contribute to their own decisions relating to their health. It also created

difficulties with practical issues such as obtaining and sharing a clear diagnosis and prognosis and hindered/limited investigations and discussion surrounding treatment options. Misunderstandings and confusion surrounding the rights of the '*next of kin*' also complicated decision-making further.

Finally, the role ambiguity participants experienced when a tenant became ill and/or died of cancer, led to a variety of both positive and negative emotions and it is to these emotions we now turn.

CHAPTER 5

Role Emotions

In this chapter the emotions participants' expressed as a result of experiencing role ambiguity are critically discussed. Experiencing sadness at the suffering and/or death of someone you know well is a natural phenomenon. However, many of the emotions participants experienced in this study resulted from a lack of clarity surrounding their role and their lack of knowledge, experience and familiarity of providing support to a tenant with cancer. For example, many participants experienced confusion concerning their new role as health advocate. This resulted in many participants feeling unable to effectively communicate with the GP and insist on their tenant being referred for further investigation. Participants were left with feelings of anger and frustration because the GP did not take their concerns seriously and act sooner. This then left participants with feelings of guilt as they wondered if they had been better equipped to provide health advocacy, perhaps the GP would have referred their tenant for further investigation sooner.

Role emotions is the theoretical category in this chapter and results from two focused codes: '*positive emotions*' and '*negative emotions*'. Table 7

presents the focused and initial codes developed from discussions with participants surrounding their feelings. Each initial code is discussed below.

Table 7 Theoretical category and focused codes relating to role emotions

THEORETICAL CATEGORY	FOCUSED CODE
Role emotions	Positive emotions
	Negative emotions

5.1. Positive emotions

In this study, participants expressed a variety of positive emotions as a result of experiencing role ambiguity. These positive emotions seemed to directly relate to their own experiences as well as those of the tenant with cancer and enabled them to make sense of what was happening. These experiences and emotions appeared to empower participants to take positive and decisive action, which directly benefited the tenant and themselves.

During the tenants' illness, two participants felt ***sympathy*** towards the tenant. Following her breast cancer diagnosis, Kelly, key worker to Joyce, sympathised with Joyce when she wanted to keep things as normal as possible. Another support worker, May, found '*keeping things normal*' difficult. This impacted on May's emotional wellbeing as having known and worked with Joyce for many years she became emotional at the news of

Joyce's cancer. May found it very difficult to control her feelings. May's difficulty in controlling her feelings impacted on Joyce's emotional wellbeing and created tensions between Kelly and May:-

May would go straight in and go 'it's all right Joyce you're going to be...' and then Joyce would be sort of worrying and I would be going 'May, stop it, stop it'. Joyce wants everything normal, you know she just wants to go through the motions of it really to be honest and I could quite kind of sympathise with that (Kelly, key worker to Joyce).

Many social care workers have supported their tenants for many years and established close relationships. Unsurprisingly they become distressed when a tenant becomes seriously ill, making the tenant's request to '*keep things normal*' extremely challenging for staff. Anna, senior support worker to Jim, felt really sorry for Jim when the GP would not listen to her concerns about his deteriorating health:-

I felt really sorry for the service user (Anna, senior support worker to Jim).

Staff reactions to a tenant's illness directly impact on the tenant. As a result of the close relationships they sometimes share, tenants are quick to pick up on their social care workers' behaviour and/or reactions and vice versa (see page 249 for further discussion on picking up on body language).

Despite all participants appearing to experience role ambiguity as a result of their tenants' cancer diagnosis, two participants viewed this role ambiguity positively. They argued it created **a challenge** for them that enhanced their existing role. Lorraine, support worker to Joyce, explained how Joyce's cancer had extended her normal working practices and made her think more:-

It will tax my brain more ... because you do everything automatically don't you? So because Joyce is poorly it makes you think more.... It doesn't make me feel vulnerable because I am quite up for doing it and I feel confident in myself. I think I am capable of doing it.... I can handle it. I am pretty strong (Lorraine, support worker to Joyce).

Mary, support worker to Graham, also commented on how experiencing these challenges had made her stronger:-

I've got to be honest, that type of job, it makes you stronger. It don't make you afraid of anything (Mary, support worker to Graham).

Both Lorraine and Mary had previous experience within a healthcare environment prior to working as a social care worker, although Lorraine's experience was in an institutional setting some time ago. Mary's experience was relatively recent in a nursing home. Interestingly, whilst other participants also had some previous experience of working in a healthcare

environment they did not perceive their role ambiguity in the same way as Lorraine and Mary. They viewed their role ambiguity negatively.

No demographic pattern could be found between those participants who perceived it positively and those who perceived it negatively. For example, both Lorraine and Lorna supported Joyce through her cancer. Lorraine viewed the changes and lack of clarity surrounding her role positively and as a challenge, whereas Lorna viewed them negatively and left her feeling vulnerable.

On repeated in-depth analysis, the only parallel that could be drawn related to the levels of exposure participants had had to a healthcare environment with those having the longest exposure demonstrating a more positive attitude to their role ambiguity and those with the least exposure demonstrating the most negative attitude. This may suggest that participants who had longer exposure to a healthcare environment were able to build resilience to the challenges they faced. This resilience facilitated Lorraine and Mary's ability to convert negative emotions resulting from their role ambiguity to positive emotions.

Whilst only two participants viewed the changes in their roles entirely positively, three participants reported feelings of **satisfaction** in knowing they had done their best for the tenant. They were pleased they had been able to contribute to the tenant's wellbeing during their illness and/or subsequent

death. Kelly reported how she gained personal satisfaction from helping Joyce during her illness: -

I got a lot of satisfaction from knowing Joyce went through the most horrendous thing in the best way she could of and that meant so much to me (Kelly, key worker to Joyce).

Similarly other studies (Wiese et al 2012, Todd 2013) report how staff were committed to providing this type of support and how privileged they felt at having the opportunity to do so (see page 254 for further discussion on providing palliative care).

Some participants felt a sense of **pride** in their ability to provide the support the tenant needed at such a vital time. Mary reported how she felt proud she had supported Graham throughout his illness and right up to his death, helping to ensure he died where he had wanted to die, at home: -

I was so pleased that he had everything that he wanted at home, that there were staff there to do at home for him because he didn't like hospitals. I didn't want him to be on his own. I was so proud that I had done from the beginning and had seen it right through to the end (Mary, support worker to Graham).

This feeling of staff doing their best for the tenant seemed very important to the majority of participants. Similarly with Todd's (2013) findings, they stated it was the last thing they could do for the tenant and providing this support became almost a point of honour. In many ways it was their personal way of saying goodbye respectfully to a tenant. Ironically, whilst providing palliative care seems to have created role ambiguity for staff, challenging them in ways they felt they were under-equipped to deal with, it also provided them with a way of demonstrating their commitment to their tenant and their role.

Several participants reported they felt a sense of **relief** when the tenant died or in Joyce's case successfully recovered from the anaesthetic following her operation. Betty, manager of the team supporting Joan, reported how she felt relieved to know Joan was not suffering anymore: -

It was right for her die. I think it was the relief that she was not suffering anymore (Betty, manager of the team supporting Joan).

This sense of relief may demonstrate the participant's depth of feelings for their tenant. It may also indicate the distress staff experienced in providing this support. Studies conducted by Brown et al (2003) and Todd (2004) identified that under-prepared staff who support tenants with their end of life care needs, experience additional stress.

During the interviews several participants stated they ***felt better*** having had the interview and the opportunity to discuss their feelings concerning the events of the tenant's illness and/or subsequent death. For example, at the end of May's interview when she was thanked for participating, she responded by stating the interview had been good for her and given her an opportunity to have a cry:-

But it does me good because now I have had that cry I will feel a bit better
(May, support worker to Joyce).

This reaction seems to identify how social care workers may be struggling with their emotions concerning the tenant's illness and/or subsequent death. Having the opportunity to talk about their feelings and emotions appeared to have a positive effect on them. This raises questions concerning their need to express and discuss their feelings and may indicate their need to access professional support. Whilst service organisations insist counselling provision is available to staff, the very nature of the staff role identity and their need to display emotional strength may prevent many staff from accessing services (see page 185 for further discussion on being strong). This combined with the lack of recognition by service organisations of the emotional dimension of support work (Todd 2013) (see page 249 for further discussion on the emotional dimension of support work), may result in many support workers being left with distressing feelings to deal with alone.

5.2. Negative emotions

During this study participants expressed a series of negative emotions. These resulted from feelings of confusion surrounding what they felt they should have provided but felt under-equipped to provide. This lack of knowledge, experience and familiarity of supporting a tenant with cancer, left participants' experiencing role ambiguity and at an increased risk of burnout. Burnout has been linked to both stress and role ambiguity (Tunc and Kutanis 2009, Ryan et al 2011, Herber and Johnston 2012). (See page 166 for further discussion on burnout). These negative emotions also related to the participant's personal situation such as their family experiences of cancer. There was a significant range of negative emotions expressed, from feelings of frustration to anger. Many of these feelings were a result of problematic access to primary and secondary healthcare. Many participants felt vulnerable, abandoned, frightened and over-burdened with the responsibility of supporting a tenant at home during their illness. These negative emotions combined and compounded the usual feelings associated with bereavement, such as guilt.

The majority of participants reported feelings of **frustration**. This frustration resulted from the GPs unwillingness to take seriously the social care workers concerns regarding the tenant's deteriorating health status. Anna became so frustrated at the GPs behaviour she considered making a formal complaint about him: -

Upset and frustrated and I really wanted to make complaints about the GP. That's how I really felt. I said to my manager, 'I would love to complain about the GP' (Anna, senior support worker to Jim).

Being the gatekeepers to further medical investigations such as blood tests, scans, and X-rays, GPs play a vital role in ensuring cancer is detected quickly and appropriate treatment commenced (see page 215 for further discussion on unsupportive GPs).

The majority of participants felt angry at the lack of support and openness by healthcare staff concerning the tenant's health status. Bob expressed his **anger** at not being told sooner of Graham's condition:-

I was angry that we weren't told sooner. Surely there should have been.. the doctors must have known but they didn't bloody tell us (Bob, support worker to Graham).

In a recent study exploring the experiences of both paid social care workers and family carers supporting adults with Down's syndrome and dementia (McLaughlin and Jones 2010), carers reported that being informed of the tenant's diagnosis ended the uncertainty surrounding the tenant's changes in behaviour. This study concludes that carers have different information and support needs at different times during a tenant's illness but insists professional and family support are vital to carers throughout the stages of

the tenant's illness. From Bob's comments above, this support seemed to be lacking throughout his experiences of supporting Graham and left him with an array of negative emotions.

Twelve participants reported how at times they felt stressed during the tenant's illness. Participants' **stress** levels increased as a result of the different challenges and issues they experienced. As previously stated, stress is associated with burnout (see page 166 for further discussion on stress and burnout). At the time of writing, whilst none of the participants experienced burnout, the majority of them were possibly at an increased risk of experiencing it. For example, some staff reported increased stress levels when dealing with the GP and/or when they tried to gain a diagnosis/prognosis from healthcare staff.

Betty reported how she had found telling Joan about her illness in a way she would understand, whilst at the same time providing the staff with the information and support they needed, particularly stressful: -

I think the stresses were finding a way to explain it to her in a way that she could understand and make her own decisions you know? I suppose for myself as a manager, I had everybody coming to me and I'm thinking... oh (Betty, manager to the team supporting Joan).

Whereas for Bob, covering shifts and ensuring tenants were being adequately supported were stressful. As was the immediate dismantling of the staff team supporting Graham after he died: -

It was stressful in that we knew we had to cover shifts. We knew Graham had two staff and we had other tenants in the house as well and they had to be manned which was another two, so sometimes there was four on shift which was very unusual for us because normally it's two. But I think the team done well (Bob, support worker to Graham).

Stress levels were additionally heightened as participants felt **the burden of responsibility** of supporting the tenant through their illness. Kelly stated when Joyce came home from hospital after having her mastectomy that she was worried whether everyone would remember what to do with Joyce's post-operative pumps and drains: -

I just remember when Joyce came back and you had to keep emptying these pumps and the drains and you always had to the shut the top one before you opened the bottom one and I just kept thinking everybody does know that don't they? And worrying about all that (Kelly, key worker to Joyce).

Similarly Rachel was worried how her staff team were going to cope with the responsibility of Neil's illness:-

What worried me was how the staff team were going to cope because it is not me that has got to go in there day in and day out, I mean it really isn't. You know I do all that I could but inevitably it is a lot of responsibility for the staff and I worried about how they are going to cope with it. You know, I mean the emotional impact as well (Rachel, manager of the team supporting Neil).

At times participants felt managers and the service organisation as a whole had abandoned them. The manager of the team supporting Graham was absent for a significant amount of Graham's illness and one of the senior social care workers informally took responsibility of the staff team supporting Graham. As a result the majority of the staff team were left **feeling abandoned** both by the manager of the project and the service organisation as a whole: -

I do think the staff team felt at the time as if they'd been hung out a bit to dry, abandoned and left to get on with it (Michelle, senior support worker to Graham).

Bob reported how he felt the team were just left alone to support Graham:-

I mean we were just left to get on with it. Just left to get on with it (Bob, support worker to Graham).

A lack of organisational support has also been linked to burnout in learning disability staff and wider in human services personnel generally (Devereux et al 2009). In an Australian study conducted by Mutkins et al (2011), investigating stress and depression in learning disability services, 80 support staff reported through the use of a short survey, less workplace support directly related to increases in emotional exhaustion and depression (Mutkins et al 2011). The findings from this study report staff experienced a lack of organisational support and therefore, may have been further exposed to the risk of burnout.

One participant stated she felt vulnerable as a result of being left to support the tenant with cancer. Although she went on to explain that being part of a team had helped to alleviate feelings of **vulnerability** by having others to reassure her that she was making the right decisions and at times offering her a second opinion: -

Working as a team helps to eliminate that vulnerability because you can always call on someone and say come and have a look at this and get a second opinion (Lorna, support worker to Joyce and Ben).

Colleagues' support and reassurance was vital in helping participants to clarify the confusion surrounding their role and compensate for the lack of knowledge and experience they felt when having to perform new tasks. This

support and reassurance helped to alleviate aspects of their role ambiguity by turning negative emotions into positive ones.

The majority of participants reported feelings of **shock** at various stages during the tenant's illness and/or subsequent death. Some reported feeling shocked when they witnessed the tenant post-operatively because of the medical equipment they were attached to, such as drains and pumps. Others described their shock at the scar on the tenant's body after surgery. Several reported being shocked at the speed at which some tenants' health deteriorated. In a recent study conducted by Todd (2013) findings suggest shock can sometimes be attributed to the way death seems inappropriate in the residential setting. Todd (2013) suggests residential settings are largely viewed as places of living, learning and teaching. The feelings of shock many participants experienced demonstrate their lack of awareness of the issues surrounding supporting a tenant with cancer and again highlight their emotional reaction to the role ambiguity they experienced as a result of being under-equipped to provide this support.

Some participants spoke of the **fear** they experienced during the tenant's illness. Fear can be an indicator of staff stress (Ryan et al 2011). Fear expressed by participants related to their ability to cope with the demands of supporting their tenant. In particular, participants were fearful of their ability to provide adequate pain relief. This was compounded by their fear of the unknown as the tenant became more ill. For example, Vanessa, support

worker to Joyce, reported how frightened she was when providing support to Joyce post-operatively: -

It was quite frightening and devastating especially when she had her drain bags. I was scared to touch the bags. I was like, oh, will I pull anything?
(Vanessa, support worker to Joyce).

The negative emotions that many participants experienced sometimes left them feeling **disempowered**. Many participants felt they were not being heard or taken seriously and their input was not required or valued by medical staff (see page 228 for further discussion on participants feeling undervalued by healthcare staff). Anna reported how medical staff did not listen to her concerns:-

We were all pushing, oh but I was fed up with pushing. I just wasn't being heard (Anna, senior support worker to Jim).

Participants sometimes felt disempowered to provide the support the tenant needed. A lack of understanding and incorrect use of the Mental Capacity Act (2005) and a lack of awareness by healthcare staff concerning the relationship between social care worker and tenant combined to leave participants feeling disempowered. For example, Janet describes how they felt disempowered when Jim was admitted to hospital for emergency treatment:-

There was no power there. Whereas if we were family, we could have said 'this is what's going to happen and you are not telling me what to do. This is what you should be doing'. That's what you can do as a family but we couldn't do that (Janet, manager of the team supporting Jim).

Grief can create intense emotional distress (Stroebe et al 1993) and presents itself in a variety of ways. These include feelings of confusion and helplessness, anger, sadness, social withdrawal, sleep disturbance, and loss of appetite (Hansson et al 2006, Stroebe et al 2007). Within the context of this study grief was perceived as a negative emotion as it sometimes impacted on participants emotional wellbeing and may have affected their capacity to carry out their work. Cycles of grief can lead initially to shock, disbelief and denial, onto disorganisation and despair and finally adjustment and acceptance (Parkes 1996). The majority of participants supporting tenants with terminal cancer reported feelings of grief when the tenant died. They also reported other tenants' experiences of grief when the tenant died and how they (participants) tried to help the other tenants with their grief whilst at the same time trying to deal with their own bereavement. For example, Anna reported how she felt when she found out Jim had died:-

I was absolutely devastated and trying to support the other service users as soon as I heard (Anna, senior support worker to Jim).

Grief symptoms in people with learning disabilities have been misunderstood and sometimes neglected (Oswin 1991). According to Read and Elliott (2003) people with learning disabilities have often been denied the opportunity to grieve either through paternalistic approaches by staff or through ignorance surrounding their capacity to grieve (Read and Elliott 2003, Dodd et al 2005). Preparation for bereavement is considered beneficial for people with learning disabilities (Watters et al 2012) and paid social care workers can positively contribute to this process if they are prepared and adequately supported. Participants in this study, whilst mindful of the impact the tenant's death might have on the other tenants, did not participate in preparation rituals.

All of the participants continued working when the tenant died. No one took annual or compassionate leave. Several participants explained they found keeping busy helped them come to terms with their feelings of loss. One staff team was dismantled almost immediately after a tenant's death and participants involved within this team expressed how difficult they had found the immediate separation from each other as they had relied on one another during the tenant's illness for practical and emotional support (see page 250 for further discussion on lack of organisational support). As there is little recognition of the emotional dimension of social care workers' relationship with tenants, it is unsurprising that there seemed no or little recognition by service organisations of the grief staff experienced when a tenant died.

As previously discussed on page 259, in one instance a new tenant was moved into the deceased tenant's room within a matter of weeks. In contrast, in another project, a room had been left empty for over six months. Both of these situations created problems for staff and the existing tenants. The majority of participants supporting a tenant who had died appeared to still be grieving. They were tearful during the interviews and expressed significant feelings of loss, anger and guilt.

The majority of the participants expressed their feelings of **guilt** and discussed how they felt they could and should have done more for the tenant during their illness. Participants perceived '*doing more*' as not taking any annual leave whilst the tenant was ill, personally escorting the tenant to all medical appointments and communicating more effectively with the GP. They claimed they should have insisted the tenant be referred for medical investigations earlier, insisted healthcare staff provide a clear diagnosis/prognosis and convince the tenant to undergo treatment. Anna felt she had neglected Jim, despite her manager constantly reminding her they had done every thing they could for Jim: -

I really felt as though I didn't do my best for Jim. I felt as though I had neglected him (Anna, senior support worker to Jim).

5.3. A reflective account of role emotions

It is interesting to note that the emotions labelled '*positive emotions*' do not seem to be particularly positive. However, when I analysed these emotions against the numerous negative emotions, in comparison these feelings and their contexts were definitely more positive than the negative ones and demonstrated some positive attitudes by participants in comparison.

When formulating my theory and writing the sections on role ambiguity, role emotions and role resolution, there appeared to be much repetition and overlapping of themes. Initially this concerned me although when I considered it fully I came to realise that it was inevitable there would be some repetition and crossover. By discussing both the emotional reaction and the resolutions to events that have already been presented in earlier chapters, effectively, some context to these events has to be provided. The context is therefore at times repetitive but unfortunately essential if the variety of emotions and resolutions are to be presented and discussed in sufficient detail. Where possible, I have tried to eliminate some of this repetition through the use of cross-referencing.

At times I found hearing and analysing participants emotional reactions distressing. Notwithstanding, I feel very privileged to have shared these moments.

Finally as a result of conducting this study I became very much aware of my own developing insensitivity and numbness towards cancer outside of this study. This manifested itself in a variety of ways (see page 124). As I became aware of my own changing reactions to cancer, I was able to consider my responses and as I reached data saturation and started to draft my thesis, my insensitivity and numbness gradually subsided and has left me with a heightened interest and response to all issues involving cancer.

5.4. Summary

Participants experienced both positive and negative emotions as a result of supporting a tenant with cancer. Participants who experienced positive emotions had significant prior exposure to a healthcare environment and/or cancer and through this exposure appeared to have built sufficient resilience to the challenges supporting a tenant with cancer create. Through previously building this resilience they were able to turn negative emotions into positive ones. The majority of participants experienced negative emotions as a result of supporting a tenant with cancer. They felt under-equipped and sometimes confused concerning the new tasks expected of their role. This lack of knowledge, experience and familiarity with these new tasks appeared to result in participants experiencing role ambiguity. In some instances these negative feelings affected the ways in which participants coped with stressful

situations and events and left some participants feeling disempowered and potentially at an increased risk of burnout.

Findings demonstrate the majority of participants were still grieving and whilst feelings of guilt are an accepted dimension of bereavement, their feelings of guilt were further compounded by their perceived inability to do more for the tenant during their illness. Participants' willingness and commitment to support a tenant through cancer was unwavering but their actual practical ability to do more was compromised by their being under-equipped, under-prepared, and under-supported.

Findings also indicate how participants used a variety of methods in an attempt to resolve some of their role ambiguity and resulting negative emotions. For example, some participants used the staff team to provide practical and emotional support during stressful periods when they experienced feelings of fear, abandonment, burdening responsibility, vulnerability, shock, guilt and grief. The process of trying to resolve these negative emotions helped participants to build resilience and this process of resolution will be now addressed in the next chapter, role resolution.

CHAPTER 6

Role Resolution

This chapter explores the study's findings in relation to the final theoretical category in this study, role resolution. Role resolution demonstrates how staff attempted to resolve their role ambiguity and the negative role emotions they experienced as a result of supporting a tenant with cancer. For example, participants who experienced role ambiguity by being under-equipped to meet the changing needs of their tenants, felt vulnerable and looked to their staff teams for reassurance and support to resolve their feelings of vulnerability. The data reveals five focused codes and twenty-four initial codes. Table 8 presents the theoretical category and the focused codes. The initial codes will be critically discussed and highlighted in bold and italics within the text of this chapter.

Table 8 Theoretical category and focused codes relating to role resolution

THEORETICAL CATEGORY	FOCUSED CODE
Role Resolution	Staff training
	Remembering
	Leadership
	Importance of team
	Coping strategies

6.1. Staff training

Many participants reported how a lack of training impacted on their ability to perform new tasks effectively. This was particularly so for those participants providing end of life care. Despite their lack of training, several staff commented on how they had gained valuable experience from the process of supporting their tenants with cancer. They also commented on how they would do things differently if they provided this support again. This implies that some participants felt the support they provided could have been better. This ability to extract a positive dimension from the reality of feeling under-equipped by a lack of training and knowledge to deal with such events, demonstrates how several participants attempted to resolve their role ambiguity and transform negative emotions into positive emotions. This

process of offsetting negative experiences with positive ones is identical to the process of building resilience. By building resilience an individual can remain moved by an event, but is not overwhelmed by it, offsetting negative experiences with positive ones (Fredrickson et al 2003).

The majority of participants reported how they felt ***under-equipped*** and inadequately trained to meet the new challenges of supporting a tenant with cancer. This was particularly so where the tasks involved a healthcare dimension. Janet (manager of the team supporting Jim) explained how social care staff are not necessarily equipped to provide healthcare:-

The thing is you come into the caring field from this side of it and you learn nothing medical. The only thing you get trained in is epilepsy. You know, and I'm thinking, yet we are dealing with some serious health issues and very, very complex issues (Janet, manager of the team supporting Jim).

Similarly, Michelle found aspects of the healthcare support she was expected to provide to Graham, very challenging:-

There was no training. '...' It was very frightening.'...' It was very difficult and stressful. '....' We deal with medication on a day-to-day basis, but there was the issue of controlled drugs and it was a huge responsibility. '....' I asked the GP what's going to happen and he'd give me quite graphical information and I was thinking oh God, how are we going to

cope with this, you know without any medical training? (Michelle, Senior support worker to Graham).

Whilst participants expressed their concerns about how they were going to cope, despite their lack of training, there was no question of not wanting to cope. All participants seemed prepared to try and cope. This suggests that, given adequate training, staff would not only be willing and committed to providing this type of support but arguably confident and less anxious about doing so.

There is limited literature exploring support workers' education and training needs when supporting a terminally ill tenant (Tuffrey-Wijne 1997, Read 1998, Lindop and Read 2000). Although one study conducted by Ng and Li (2003) exploring the educational needs of both social care workers and healthcare workers in learning disability settings reported 23 of the 25 participants stated education and training in this area would be of benefit to them.

As previously discussed on page 199, it is recognised that role ambiguity increases stress levels amongst support staff (Hatton and Emerson 1995, Hatton et al 1996, 1999). The study conducted by Windley and Chapman (2010) in England identified how new staff initially learnt how to do their jobs through a process of *'trial and error'*. Data was collected for this study through three focus groups and five semi-structured interviews and aimed to

explore the perceptions of the training and support needs of staff supporting people with learning disabilities. However, the choice of participants in Windley and Chapman's (2010) study may have been biased as they were selected by their managers. Notwithstanding, on the job experience or learning by doing (Choi 2006) and learning from established staff seemed the most widely used form of staff training. Whilst in many residential settings staff are available to learn from one another, in others where staff are lone working and/or perhaps with one other member of staff, there may be limited opportunities to learn from example. In relation to supporting tenants with cancer, there may not be established staff with existing experience of this nature and arguably adopting a process of '*trial and error*' could be dangerous with '*on the job experience*' not always available. This could increase role ambiguity and lead to further stress, which may impact on the quality of support provided to the tenant at a crucial time.

Four participants reported how they had ***learnt lessons*** from their experiences of supporting a tenant with cancer. They reported that the lessons they had learnt would enable them to improve the quality of the support they provided if they were in a similar situation again. For example, Sue (manager of the team supporting Graham), stated what she would do next time:-

In hindsight the only thing I would have done differently was when we first met with the consultant and he started talking to us about palliative care, despite explaining to him we had no medical training. I would be saying to

him without a diagnosis we don't know the stages. We had questions like, 'if he passed away, what do we do? Do we phone an ambulance?' (Sue, manager of the team supporting Graham).

Similarly Betty (manager of the team supporting Joan) highlighted the lessons she had learnt after Joan's death:-

We have learnt things. Like the lady's room was empty for so long but I think had there been somebody moved in there a little bit sooner, it may have helped my other lady (Betty, manager of the team supporting Joan).

This demonstrates how some participants tried to offset their negative experiences by extracting the positive dimensions of their experiences to inform their future working practice. This process reveals how several participants were able to build resilience in preparation for having to provide similar support to another tenant in the future.

6.2. Remembering

The majority of participants wanted to share their memories of the tenant during their interview. Sometimes these were happy memories of times past and sometimes these were memories relating to distressing and shocking

events that had occurred whilst they supported the tenant with cancer. This process of remembering seemed to help participants come to terms with their experiences and make sense of events. As previously mentioned on page 281, the research interview sometimes provided an arena for participants to discuss and resolve some of the issues and feelings they had experienced.

The majority of participants had **memories** and stories to recall and share. Many of these were positive and made the participant laugh and/or smile. For example, Bob (support worker to Graham), remembered how Graham took pleasure in his appearance, particularly for the rugby:-

He was very proud. Always smartly dressed and he was right up until the end you know. He always wanted a tidy shirt on and you know, wanted to look good if the Welsh game was on. He would have loved this Grand Slam. He would have loved it. Saturday morning he would come out of his bedroom with his flag (laughter), all ready for the game. He loved it, loved it (Bob, support worker to Graham).

In contrast, Michelle (senior support worker to Graham) remembered how Graham was the night before he died:-

I can remember the night before he died. I was there all day and night and I had slept in and he was quite poorly and we made him comfortable. Myself and another member of staff who was there said 'he looks peaceful

now, tonight he looks comfortable' and that will stay with me that we were able to do that for him and he was surrounded by people that really cared for him (Michelle, senior support worker to Graham).

This reveals how Michelle has used this memory of Graham dying to resolve some of her negative feelings associated with the grief she was experiencing. By remembering how comfortable and peaceful Graham had looked the night before he died, and acknowledging that she and a colleague had been able to facilitate that level of peace and comfort for Graham, provided her with some comfort. Whilst Michelle was deeply affected by the events of that evening, she was able to counter balance these negative emotions with positive ones. Through this process, Michelle was able to build resilience.

Participants discussed events they would ***never forget***. The majority of these events related to shocking and/or stressful incidents that occurred during the tenant's illness and/or subsequent death. Rachel (manager of the team supporting Neil) explained how she felt when Neil telephoned her:-

The only event that actually stood out for me was when he rung me. He was afraid he was going to die on his own. That was probably the one that stuck out in my mind most. When I went down there and he was hanging on my neck crying and he was terrible and that's what's stuck in my mind most. He is a valleys man. 'Nothing wrong with me love', you

know? And then you have to ring somebody crying to admit that you were in that much pain, which was a biggie for him. It was huge for him and that does stick out in my mind the most (Rachel, manager of the team supporting Neil).

It is clear from Rachel's comments that Neil was able to share his feelings with her at a time when he felt at his most vulnerable. Arguably this interaction symbolises the depth of the relationship between Rachel and Neil. This allowed Rachel to gather comfort from the knowledge (memory) that Neil had trusted and relied on her to help him and how she was able to honour that trust and provide the help he needed. Rachel is using this memory as a way of resolving some of the negative emotions she experienced as a result of supporting Neil.

Several participants recalled events where they and the tenant had ***had fun together***. These recollections usually followed after a more serious or distressing discussion had taken place concerning the tenant's illness. For example, Anna initially talked about Jim's final days in hospital before he died and how he had tried to remove some of the medical equipment and wires. Anna followed this memory by a memory she had of how Jim had made her laugh:-

His motto was, 'it's a woman's job'. 'Is it really Jim? Now come on and prepare your food'. It was so funny, but he was funny with it. The laughter

between the two service users was lovely (Anna, senior support worker to Jim).

This process of recalling distressing memories followed quickly by recalling positive memories demonstrates how participants tried to resolve negative memories by balancing their emotional wellbeing with positive memories. As a result they were able to build resilience.

6.3. Leadership

All participants reported how essential it was to have a team leader. The team leader took overall responsibility for the support the tenant received and directed and guided staff accordingly. Having another member of staff taking responsibility for the care and support of the tenant seemed to limit participants' exposure to some of the negative emotions they were vulnerable to, such as feeling over-burdened. Where a clear leader was not present, participants were left with negative emotions resulting from both supporting their tenant and feeling unsupported while they attempted to support their tenant. Teamwork also suffered as a consequence.

Of the five different staff teams supporting the six tenants with cancer, three teams felt they had **supportive management**. They were generally satisfied with the direct line management and internal leadership they received. This

support included support from their project managers and the support the project managers received from their line managers. Participants reported that being able to talk things through with line managers, and having immediate access to line managers was particularly important. Having adequate staffing levels, access to information through team meetings and being acknowledged and appreciated for their extra commitment and work were also considered important by participants. By having supportive management some participants were able to limit their role ambiguity and restrict their exposure to resulting negative emotions such as feelings of fear, vulnerability and shock.

The remaining two teams were less satisfied with the management support they received and, as a result, experienced significant role ambiguity and resulting negative emotions, which remained unresolved at the time of interview. Their issues included poor and/or limited contact and communication and a lack of acknowledgement and appreciation for the extra commitment and work they had provided. Also a lack of information concerning the tenant and their illness, unclear leadership and feelings of being abandoned by the project/line manager and the organisation as a whole were also reported to be problematic. Despite there being a study conducted by Dodevska and Vassos (2013) exploring the qualities of support staff from the perspective of people with learning disabilities and managers of accommodation services, there are no studies exploring the qualities of leaders and managers of residential services from the perspective of support staff.

For the managers who did take an active part in supporting their team during a tenant's illness, ensuring they **looked after staff** and supported them practically and emotionally seemed important to them. Rachel, (manager of the team supporting Neil) expressed her concerns:-

I mean we support people we don't give palliative care to people. I do worry, I do and I chat with them regular but then you know what they say and what's up there (pointing to her head) and what's down there (pointing to her heart) are two totally different things aren't they? Some of the staff, it hit them you know? Some of them have been working with him for years, years and years (Rachel, manager of the team supporting Neil).

By supporting her staff and recognising the stress they were experiencing, Rachel acknowledged and highlighted their potential role ambiguity and was concerned how it would impact on their emotional wellbeing. Her statement demonstrates how she was trying to fulfil her obligations as project manager by supporting and looking after them whilst at the time of the interview, she had no way of knowing what impact providing this support would have on them.

Four of the five project managers participating in this study reported how they considered their role was **being in charge**. Their role was to organise support rather than provide it. They ensured they had sufficient staff cover to meet the tenant's needs, such as attending hospital appointments. They

ensured staff had access to the correct pain relief and decided the number of occupational therapists that might be required. They also commented on how they had a good rapport with their staff and how they were always there to listen to their concerns and worries. One manager stated that if her team were dissatisfied with her performance, she hoped they would tell her. On hindsight two managers expressed their regret that they did not support their staff enough. One suggested providing more supervision sessions with staff during the tenant's illness would have helped. All managers stated they would welcome the opportunity of increased training for their staff to better equip them to deal with the challenges they faced whilst supporting a tenant with cancer. It seems clear that participants who were managers also experienced role ambiguity and negative role emotions as a result of indirectly supporting a tenant with cancer but directly supporting their staff. It also seems clear that through the process of reviewing their performance as managers and considering what they could have done to improve their performance, they too were attempting to resolve their negative emotions.

There is a dearth of literature exploring how project managers experience supporting their staff while they support a tenant with cancer. Managers play a pivotal role between the front line staff and the organisation. Where staff experience practical and emotional difficulties supporting a tenant, managers are well placed to highlight these issues to the organisation. Organisations are then able to explore how best to support staff both internally and externally, including their health and safety obligations, organising specific training, counselling or increasing staffing levels where and when necessary.

6.4. Importance of team

All of the participants in this study relied heavily on the support of their team during the tenant's illness. This support was important during the tenants' illness and after their death. Sharing experiences, risk and expertise, supporting one another both practically and emotionally, trusting each other and being loyal to one another provided vital support for many of the participants. By utilising the team in this way, participants were able to relieve and in some instances resolve some of the role ambiguity and resulting negative emotions they experienced.

As the majority of participants felt under-equipped to meet the new and changing needs of their tenants, they relied on each other's **trust** and support. This required unquestionable individual commitment to their daily tasks, sharing concerns and worries with each other and maintaining confidentiality. This enabled the majority of participants to share and discuss their feelings and express their emotions in a safe, non-judgmental environment. It provided an arena for many participants to resolve aspects of their role ambiguity and resulting negative emotions.

It is recognised the relationship staff have with each other is important and directly correlates with their job satisfaction (Mascha 2007, Thomas and Rose 2009, Shearn and Todd 2000). As previously mentioned on page 165

it is also acknowledged that positive working relationships impact on the quality of the support social care workers provide to tenants (Ford and Honnor 2000).

All fourteen participants emphasised the importance of **teamwork**. Generally, they viewed the team as a jigsaw, with each member of staff symbolising a jigsaw piece. Each piece provided an invaluable but unique contribution to the team that together provided positive working practices and positive outcomes. These included continuity, camaraderie and support for the tenant and each other. Kelly (key worker to Joyce) explained how important the team had been to both her and Joyce:-

It's important for Joyce to have that continuity. We had such a good little team. We pulled on the people that Joyce trusted the most and Joyce liked the most and we kept that running and that was a strength for me as well (Kelly, key worker to Joyce).

In contrast when the team fragmented as a result of a disagreement, poor line management, or a member of staff did not participate as a team member, this had a significant and negative impact on the rest of the team and ultimately the tenant. For example, Lorraine (support worker to Joyce) was angry when the other members of her team did not inform her of Joyce's diagnosis (see page 195 for further information relating to this incident). Arguably, as the team provides a key arena for staff to resolve negative

emotions resulting from their role ambiguity, if these negative emotions originate from the team in the first instance, they may remain unresolved. At the time of interview Lorraine was still feeling angry and had not resolved her negative emotions.

Half of the participants reported how important it was to have **staff supporting each other**. Having someone to talk to, sharing responsibilities, providing reassurance to one another, and sharing expertise and experiences were all mentioned by participants as being important. Bob (support worker to Graham) explained how he felt about having staff support:-

The team support was cracking. It was just having someone to talk to. It could be about nothing. Do you know what I mean? But they are there
(Bob, support worker to Graham).

Bob's comments demonstrate the importance of staff supporting one another. By providing each other with support and reassurance, they help each other to resolve their negative emotions and at the same time inadvertently help each other to build resilience by offsetting their negative experiences and emotions with positive ones.

Five participants discussed how an important part of the staff support they received involved **staff loyalty**. Knowing that they could rely on each other,

regardless of the circumstances, provided a secure environment for staff to share their stress and anxiety.

Several participants described how they had shared their previous experiences of providing nursing support with other staff in an attempt to help them cope with the demands of meeting the unfamiliar needs of supporting a tenant with cancer. ***Sharing experiences*** proved vital in ensuring the tenant received quality care. It was also vital in ensuring staff were equipped to meet some of the healthcare needs of the tenant.

Over half of the participants described how they employed ***risk management*** techniques to manage and/or resolve some of the risks they felt exposed to as a result of supporting a tenant with cancer. For example, Anna (senior support worker to Jim) reported how she had developed and completed monitoring forms of Jim's deteriorating health status. Anna felt this provided her with a record of her concerns and actions and demonstrated how she had tried to persuade the GP to investigate Jim's symptoms further. By providing this paper audit of her actions, Anna felt she could prove the lack of response to Jim's symptoms was not her fault but the fault of the GP. In her view, this reduced the risk of her being blamed or held responsible for Jim's condition and provided proof that she had done everything she could for Jim.

Many participants commented on how ***bringing different things to the team*** provided rich and diverse resources of experience and specialist skills when the tenant was ill and/or died (see page 309 for further discussion on teamwork). Participants expressed how each member of staff had something to offer the tenant and this variety was essential in ensuring all of the tenant's support needs were met. Tanya (one of the managers of the team supporting Joyce) commented how staff were given certain responsibilities depending on their specific abilities:-

Yes and everybody has got so many different skills together. Each individual has different skills. So we outline so and so will be perfect for that job, she has got that skill. Another person doesn't like driving, doesn't like doing this but so and so does. So you know, delegate that job to that person (Tanya, manager of the team supporting Joyce).

The variety of staff's skill sets is important during a tenant's illness. As individual staff were under-equipped to provide comprehensive support to tenants, pooling skill sets within the team, ensured collectively the team were able to meet the needs of the tenant.

6.5. Coping Strategies

All participants in this study discussed their personal and individual coping strategies when supporting a tenant with cancer. Keeping busy, talking things through, having a good cry and taking regular breaks represented some of the coping strategies staff employed when trying to cope with the role ambiguity and resulting negative emotions they experienced.

Being thanked by the organisation, the tenant's relatives and line managers for the commitment and dedication participants had shown to the tenant during their illness was important to five participants. This '**thank you**' symbolised an acknowledgment of the work they had undertaken and made them feel valued and appreciated.

Care work is dyadic in nature (Reinders 2009), (Schuengel et al 2010) and when tenants are not socially or emotionally responsive to staff, this can produce difficult feelings for staff including guilt and anxiety (Shearn and Todd 2000). Arguably when a tenant becomes seriously ill, reciprocity and the usual dyadic process between tenant and social care worker is interrupted. This may be because the tenant is not well enough to participate in the process and/or the social care worker may have a higher expectation given their increased responsibilities. As the dyadic process deteriorates, the social care worker may feel the need to look elsewhere for acknowledgement and gratitude, thus the need for a triadic relationship emerges. This may also explain why it was important for some participants to be thanked by a third party during this study. A lack of reciprocity between organisations,

support staff and tenants can also be linked to burnout (Thomas and Rose 2009).

Half of the participants had had ***previous experiences of cancer***. These sometimes related to family members, participants themselves and exposure through previous employment such as working in a nursing home. These experiences, although sometimes limited, helped to take the fear out of the unknown, reduced role ambiguity and helped participants to cope with the challenges they faced when supporting a tenant with cancer. Kelly (key worker to Joyce) explained how she had learnt from her previous experiences of cancer:-

Once you've been through it a few times, you don't harden, but you learn. I think I learnt from experiences (Kelly, key worker to Joyce).

Kelly's comments demonstrate how, through her past experiences and exposure to providing cancer support, she had already built some resilience to the demands of providing cancer support. Social care workers who share their previous experiences and knowledge of cancer with their colleagues, indirectly help to equip their colleagues for the challenges supporting a tenant with cancer might bring. In a recent study exploring staff views on the importance of relationships for knowledge development, Bradshaw and Goldbart (2013) report staff learning from within their own teams is more successful than learning from external knowledge such as reports and books.

All participants discussed a variety of ***coping*** techniques they used during the tenant's illness and after their death. Having a 'good' manager was considered valuable. Participants perceived a 'good' manager was someone who listened and who was always available. Keeping busy, sharing experiences and memories with each other, having a good cry, going for long walks with a partner or a dog, and having regular coffee and cigarette breaks were some of the daily and weekly coping strategies participants discussed. They recognised these activities as their coping techniques. All of these techniques provided a similar outcome; being able to carry on providing support to the tenant either within the next hour, the next day, week or month. None of the participants reported maladaptive coping strategies, although they may well have used them but did not feel able to disclose.

Five participants in this study reported how staff needed to ***prepare themselves for the worst***. They explained how they lacked coherent information concerning the tenant's cancer, the stages of the cancer and had no idea of what to expect concerning the tenant's illness. This lack of coherency, resulted in several participants discussing their inability to prepare themselves for the worst and left them wondering how they would cope with the different stages of the tenant's illness. They also highlighted the need for all staff supporting a tenant with cancer to be better informed concerning the type of cancer and, where possible, the different stages of that cancer (see page 235 for further discussion on accessible information).

There is some accessible cancer information for people with learning disabilities and social care staff in a variety of formats from organisations such as Macmillan and Tenovus. Accessible information formats include telephone information lines, access to specialist nurses and drop-in centres (see page 237 for further discussion). During this study, some participants reported accessing information such as leaflets through their line managers. They did not report accessing information independently or through any other means. It is unclear why staff seemed unable to proactively seek out this information and it seems equally unclear why service organisations did not ensure this information was provided in a variety of formats as a matter of course.

Both Kelly (Key worker to Joyce) and Rachel (manager of the team supporting Neil) reported how they met their challenges by taking **one day at a time**:-

We didn't really tell Joyce initially that she had cancer. We said she had to have this operation to remove the lump that she was aware of and then we would take it from there. I used to say 'Joy shall we take it one day at a time?' and she would say 'that's what we'll do shall we? We'll take it one day at a time' (Kelly, Key worker to Joyce).

This demonstrates Kelly and Joyce's coping strategy. They were both content to take the events and outcomes of Joyce's cancer on a daily basis

thus limiting their daily exposure to the stresses of cancer. Arguably this approach facilitated Kelly to resolve any negative emotions on a day-to-day basis.

Participants employed a variety of ways of ***moving on positively*** from the tenant's death. Several participants reported how they encouraged the other tenants to talk about the deceased tenant and keep and display photographs in their rooms and in the communal areas within the house. They suggested this allowed everyone to come to terms with their loss slowly and together. Two participants discussed how moving a new tenant into the house after the tenant's death in a timely and respectful way helped them and other tenants to come to terms with their loss by having someone else to focus on. One participant reported how she and the other tenants would often visit the tenant's grave together and leave fresh flowers. By moving on positively, participants are attempting to resolve their negative emotions, and in this instance these emotions represent their feelings of grief. Whilst studies have been conducted exploring the bereavement needs of people with learning disabilities (Dodd et al 2008, Campbell and Bell 2010, McEvoy et al 2010, Watters et al 2012, Read et al 2013, Handley and Hutchinson 2013) there is a lack of research exploring the bereavement needs of social care workers.

Many participants discussed how supporting a tenant with cancer impacted on the other tenants and that ***keeping things normal*** was vital for the other tenants' sense of wellbeing during the tenant's illness and after their death (see page 209 for further discussion on tenants' grief). Participants reported

that keeping things normal symbolised normal daily routines to tenants who, as a result, were less likely to get upset and become unsettled. This in turn ensured staff were able to cope with their daily duties and their own emotions and grief, with minimal disruption. Mary (support worker to Graham) explained how other tenants would become stressed if they thought she was stressed:-

He was a good character (Graham) and they all missed him and you'd have one, well she was very repetitive and she would be asking 'how is he?' all the time and her stress levels would go up. So if she could see us stressed and the others, it would have been chaos, really chaos. '...' Yes you try and keep everything running smoothly really (Mary, support worker to Graham).

Mary went on to describe an incident that occurred when Graham's family had come to visit and the other tenants were very excited and getting ready to go to a local BBQ. Mary recalls feeling anxious and worried that she would be unable to cope as she tried to balance a variety of tasks associated with organising and participating in both events. The tenants sensed her anxiety and started to become distressed, which in turn only increased Mary's anxiety. Keeping things normal symbolises the way participants tried to maintain the equilibrium within the house after the tenant had died. This demonstrates how participants attempted to resolve heightened emotions associated with feelings of grief.

Going home to family and loved ones provided a coping strategy for one participant. Betty explained how lucky she felt at times that she was not a family carer:-

We love them to bits. No matter what they do. I suppose we are lucky we can go home because there are people that are supporting people with learning disabilities 24/7. It must be so hard because at the end of the day we can go home (Betty, manager of the team supporting Joan).

Some participants reported how **getting back to normal** after a tenant's illness and/or subsequent death was an important way to resolve negative emotions. Where a tenant had died participants seemed resigned to their loss but also relieved (see page 275 for further discussion on positive emotions). The relief had two dimensions. Firstly participants were relieved that the tenant was no longer suffering. Secondly participants were relieved their role had returned to its former identity and the new and unfamiliar challenges they had encountered whilst supporting their tenant with cancer, had been resolved.

6.6. A reflective account of role resolution

Overall I found analysing these findings and writing this chapter rather uplifting. Being aware of the many difficult and stressful challenges

participants had faced during their experiences of supporting their tenants with cancer, I found it quite extraordinary that many of them were able to see '*light at the end of the tunnel*'. Their reliance on and trust of each other was unwavering and their ability to convert their negative emotions into positive ones was inspiring. At the same time I was still very much aware of the grief they were experiencing and at times, particularly during the interviews, I felt completely helpless. In many ways my emotional reactions to theirs fuelled my commitment to continue with this study and during my most challenging hours has provided the impetus to carry on.

6.7. Summary

This chapter has reported on how social care workers attempted to resolve their role ambiguity and resulting negative emotions when supporting a tenant with cancer. Participants engaged in a variety of activities and strategies to resolve their negative emotions. The importance of leadership and of team emerged as two key themes where participants tried to resolve much of the role ambiguity and resulting negative emotions they experienced by relying on each other's support and by being guided by someone who held overall responsibility. By drawing on a variety of coping strategies, participants were able to continue to provide their support and meet the changing needs of tenants.

Despite the participants' lack of training, they described how they had learnt from their experiences and discussed how their experiences might inform their future practice. Through reflexivity they were able to consider and make sense of their actions and resolve some of their negative emotions. This consideration has helped to inform their future practice and enabled them to build resilience in preparation for when they support another tenant with cancer in the future.

Having now presented and critically discussed the four theoretical categories and their relevant focused and initial codes, the next chapter will present the emerging theory and critically discuss the core category of building resilience.

CHAPTER 7

The Emerging Grounded Theory

In keeping with the principles of constructivist grounded theory, this study has generated data grounded in the research participants' experiences of supporting a tenant with learning disabilities living with cancer in residential services across Wales. By following Charmaz's (2010) flexible guidelines to conduct constructivist grounded theory, it has produced findings that are true to both the research participants' and researcher's shared experiences. Whilst the experiences of supporting a tenant with cancer are those of the participants, the resulting theory is an interpretation of those experiences by the researcher. By employing a symbolic interactionist perspective, data collection and simultaneous analysis was conducted addressing the subjective meanings participants imposed on their experiences. The iterative process of moving back and forth between the data and analysis helped to rationalise the data, making data collection more focused and the analysis more theoretical. Initial and focused coding captured the patterns and themes within the data and together with constant comparative analysis, theoretical sampling and gaining theoretical sensitivity, exposed the possible relationships between code and category. This facilitated the abstraction from substantive code to theoretical category. By illustrating the findings of this study in a literary style rather than scientific, and by using raw data within

the text, this thesis is evocative of the experiences of the participants. This enables the reader to go beyond the surface of the data and question tacit meanings about the participants' values and beliefs. By using constructivist grounded theory to investigate participants' experiences of supporting tenants with cancer, a theoretical framework has been developed that captures the cycle of building resilience (the core category).

According to Charmaz (2010), presenting the theoretical framework should demonstrate how a grounded theory expands, improves, challenges and goes beyond existing concepts. It should also locate the argument made. For example, the theoretical categories should help to explain how the key ideas have been conceptualised.

In this study the theoretical categories of role identity, role ambiguity, role emotions and role resolution capture and conceptualise the focused codes. Alongside this they come together to form the theoretical framework. This framework locates the argument made by expanding, improving, and then synthesising a more refined, extensive concept of the core category, building resilience. For example, according to Tunc and Kutanis (2009), Ryan et al (2011) and Herber and Johnston (2012), role ambiguity and the resulting stress and anxiety has been linked to an increased risk of burnout amongst staff. The grounded theory emerging from this study expands and improves upon this finding, by demonstrating how role ambiguity and its resulting stress and anxiety is developed, can be overcome and possibly even avoided through the cycle of building resilience. This demonstrates how the

theoretical framework generates a synthesised and more refined, extensive concept of role ambiguity.

Table 9 overleaf provides an overview of the emerging codes and categories leading to the core category.

Table 9 Theoretical categories and focused codes of this study

FOCUSED CODE	THEORETICAL CATEGORIES	CORE CATEGORY
Staff profile Staff know best Staff commitment Special relationship Being strong Being professional	Role identity	BUILDING RESILIENCE
Tenants' barriers Healthcare barriers Knowledge barriers Internal barriers External barriers Communication barriers	Role Ambiguity	
Positive emotions Negative emotions	Role Emotions	
Staff training Remembering Leadership Importance of team Coping Strategies	Role Resolution	

Figure 3 Cycle of building resilience

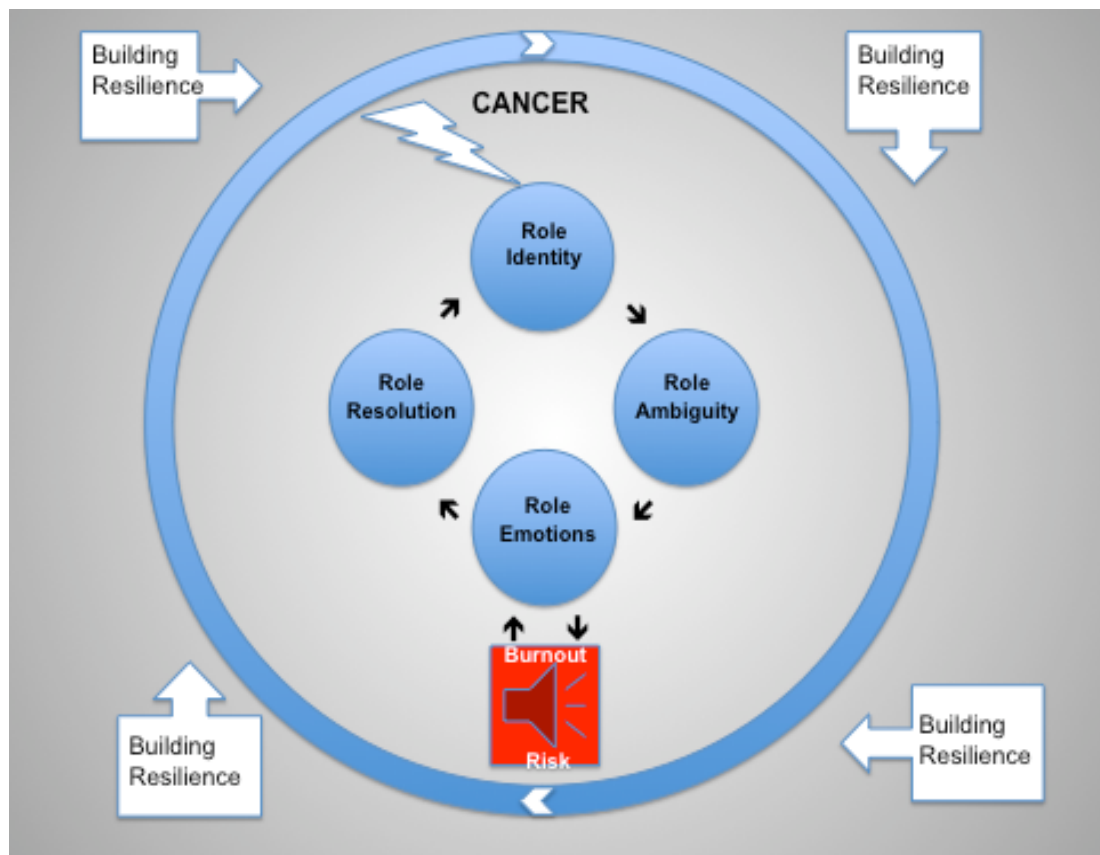


Figure 3 above provides an overview of how the theoretical categories relate to one another to form a theoretical framework. The implications of and relationships between the theoretical categories and how they relate to building resilience will be explored within this chapter.

7.1. Resilience

Building resilience is posited here as the core category emerging from the cycle of building resilience, which involves the other four theoretical categories of role identity; role ambiguity; role emotions; and role resolution. These theoretical categories help to explain how participants somehow managed to get through their experience of supporting a tenant with cancer and through this process were able to build resilience. Resilience will now be critically discussed and its relationship to the theoretical categories will be examined.

Resilience is concerned with an individual's ability to adapt to stressful situations. Conceptually, resilience refers to the resistance of risk, adversity and/or stress (Broberg et al 2009). Resilience results from basic human adaptation systems. Resilient individuals can remain deeply moved by events, but are not overwhelmed by them, offsetting negative experiences with positive ones (Fredrickson et al 2003). It is perceived to be an adaptive state, not just a personality trait, (Luthar et al 2000) and is not considered rare but a healthy way of adjusting to difficult situations such as bereavement (Masten 2001, Galea et al 2003). According to Hunter (2001), conceptually, resilience appears to cross national and cultural boundaries and is understood as having the capacity to '*bounce back*' and/or resist adversities.

More widely, resilience appears to attract a variety of definitions and uses. In a recent study conducted by Kilka and Herrenkohl (2013) reviewing development research on resilience in maltreated children, it is suggested there is disagreement amongst researchers as to the meaning of resilience with different definitions and different methods being used to study it. They further suggest this has resulted in problems when trying to systematically compare studies and has resulted in little being learnt about the patterns of resilience (Kilka and Herrenkohl 2013).

Resilience has been explored within a variety of fields such as developmental psychology, formative psychology and competence under stress and recovery from trauma and has been used extensively in research surrounding the resilience of children. For example, the International Resilience Study (Grotberg 1997) involved approximately 600 children, aged 11 across 30 countries that were surveyed concerning their most common adversities. Within this study, adversities reported by frequency were the death of parents and grandparents, divorce, parental separation, illness of parents or siblings, poverty, moving home, accidents, abuse, abandonment, suicide, remarriage and homelessness (Grotberg 1997). The study described resilience as

'A universal capacity which allows a person, group or community to prevent, minimise or overcome the damaging effects of adversity'
(Grotberg 1997:7).

More recently resilience and has been linked to research surrounding bereavement and palliative care (Monroe and Oliviere 2007, Ablett and Jones 2007, Machin 2014) whereby key aspects of palliative care are being explored through a resilience perspective. Monroe and Olivere (2007) suggest that through the various levels of planning and delivering palliative care, there appear to be many opportunities to maximise coping, facilitate change, build an infrastructure for self help, and increase the capacity of teams and organisations. Most recently (Machin 2014) a unique model has been developed that helps health and social care practitioners to explore resilience within loss and grief.

Masten et al (1990) proposes three types of resilience; those who do not give in to physical adversities such as having a low birth weight, those who develop coping strategies in situations of chronic stress such as children whose parents are chronic drug users and, those who having suffered extreme trauma such as being involved in a natural disaster but who have recovered and flourished (Gibson 1998).

In contrast, other scholars (Garmezy 1994, Brown and Rhodes 1991) suggest there are three broad factors associated with resilience; family support, a supportive agency and/or person outside of the family, and individual characteristics such as self-esteem and temperament. Ungar (2003) further suggests there is a fourth factor, culture. According to Atwool (2006) resilience is not one individual characteristic, she argues that research indicates there is a combination of both external and internal factors

that contribute to resilience and that these can combine to produce protective effects such as those connected to attachment theory (Atwool 2006). More recently, Cichetti (2010) suggests that over the past decade there has been an increasing move to examine the neurobiological and/or genetic correlations and contributions to resilience. This has enabled researchers to explore resilience from a multilevel perspective exploring both the biological and psychological aspects of behaviour associated with resilience (Cichetti 2010).

Resilience has also been explored in research involving individuals with mental health issues and with adults experiencing trauma (Rutter 1979, 1987, Fredrickson 2001, Tugade and Fredrickson 2004, Ong et al 2006, Cohn et al 2009, Davydov et al 2010). More recently, a Norwegian study was conducted exploring resilience in staff working with people with learning disabilities in both community and institutional settings who displayed offending behaviour (Sondenaa et al 2013). Findings from this study concluded those staff in local community services had higher resilience compared to those in an institutional setting although this is apportioned to the numbers of people with learning disabilities they were working with and the institutional demands they may have faced (Sondenaa et al 2013). In the following section, the cycle of building resilience is explored through the examination of its relationship to the four categories.

7.2. The relevance of the four theoretical categories to the cycle of building resilience

In this study participants were propelled into a cycle of building resilience when their tenants became ill with cancer. Currently the social care worker role identity is challenged when a tenant becomes ill. Social care staff are not required to have any prior healthcare experience and/or healthcare training. Yet findings from this study indicate providing elements of healthcare support to their tenants with cancer is becoming a new and essential dimension of their role. This dimension appears to be neither acknowledged nor supported by service organisations, with social care workers' job descriptions making no reference to or outlining any requirement to undertake any healthcare related task. As a result participants' role identities were challenged when a tenant became ill and participants were expected to meet the tenants' changing needs by carrying out new and unfamiliar healthcare tasks, which they felt under-equipped to provide.

This created confusion and a lack of clarity surrounding the expectations of the social care worker role for not only the social care worker, but also for others working/involved with the social care worker such as health professionals and relatives. The social care worker was not sure whether these duties were part of their role and generally did not feel adequately equipped or supported to provide them. As a result participants

experienced role ambiguity. This role ambiguity resulted in participants experiencing a series of emotions.

Role emotions represent the emotional responses of participants to the role ambiguity they experienced. For example, when participants encountered unsupportive GPs, which they felt under-equipped to challenge, they were left with negative feelings of anger, frustration and stress. The role emotions participants experienced were predominantly negative and left them vulnerable to burnout. Whilst none of the participants seemed to have experienced burnout they were exposed to a number of risk factors and others may experience stress and burnout in a similar situation.

Participants attempted to resolve these negative emotions by converting them into positive emotions, offsetting negative feelings with positives ones (Fredrickson et al 2003). They did this by gaining support and reassurance from their teams, exercising coping strategies, accessing training (where available) and remembering the special relationships and moments they had shared with their tenants. All of the participants in this study appeared to have achieved role resolution.

When the tenant recovers or dies, the social care worker is left with a higher level of resilience. This in turn informs their role identity and places them in a more resilient position should they encounter a similar situation in the future. However, the cycle would be broken if social care workers were unable to

offset their negative feelings with positive ones. In this event they might experience burnout and stress rather than role resolution.

Whilst participants achieved role resolution, this was largely by accident. However, by gaining an understanding of the situation offered by the theoretical framework presented in this study, there are areas where agencies could intervene and reduce the risk of stress and burnout. As previously highlighted by Monroe and Oliviere (2007) (see page 330), by providing adequate training and support before supporting a tenant with cancer, social care workers would have the opportunity to build prior sufficient resilience to the challenges supporting a tenant with cancer brings.

7.3 The implications of the theoretical framework for taking a more proactive approach to building resilience.

Findings from this study suggest by achieving greater clarity surrounding the expectations of the social care role prior to a tenant becoming ill, through incorporating a healthcare dimension into the social care role and through the provision of adequate training and support, elements of role ambiguity could be eliminated and prior resilience could be built. Additionally, if job descriptions clearly reflected and outlined the tasks expected of the social

care role, such as providing health advocacy and/or providing palliative care, further confusion and role ambiguity could also be limited. As a result, this may give rise to training requirements. However, by healthcare support being clearly defined as an expectation and duty, social care workers would be able to adopt this new dimension and adjust their role identities accordingly.

Findings also indicate that the participants were deeply committed to meeting the changing needs of their tenants despite their lack of training and experience. Therefore, with staff already prepared to provide this new support, it appears there would be little resistance to formally adopting these new dimensions to their existing roles.

The majority of participants in this project reported problems associated with joint working practices across other agencies, such as those involved in providing primary and secondary healthcare. A greater understanding and value of the vital and pivotal role social care workers play in supporting their tenants with cancer could enhance joint working and ultimately improve the timeliness and quality of care tenants with cancer receive.

Half of the participants in this study reported they were still experiencing the negative emotion of guilt concerning the support they provided their tenant with cancer. Whilst guilt is a recognised stage of bereavement, participants' guilt also appeared to be closely connected to the role ambiguity they

experienced. For example, they explained how they should have done more for their tenant during their illness, such as being firmer with the GP and demanding a referral for investigations sooner. This guilt seemed to stay with participants long after other negative emotions such as frustration and anger had been resolved. These findings may help service organisations to acknowledge the emotional component of social care work, and emphasises the need for staff to receive greater supervision and professional support such as counselling during stressful and distressing periods.

Findings suggest that by training the entire team, consistent and comprehensive support could be provided. This would allow staff to share responsibilities and reduce individual feelings of stress and feelings of being over-burdened (see page 282 for further discussion on negative emotions). Currently staff support is not comprehensive or consistent and teams rely on each member of staff having a particular skill, which combined can usually meet the needs of the tenant (see page 313 for further discussion on bringing different things to the team). This places a heavy reliance on particular members of staff to always be available and makes them fearful of the tenant's welfare if they are not available. They then become reluctant to take time off for a holiday and/or illness.

By having a fully equipped and adequately resilient team, staff concerns surrounding risk management could also be reduced (see page 312 for further discussion on risk management). For example, if staff already have adequate training and sufficient resilience to meet the new challenges of

supporting a tenant with cancer they may be less inclined to make mistakes and less inclined to worry about making them.

In conclusion of this section, the cycle of building resilience suggests service organisations are not engaging in the challenges their staff encounter when supporting tenants with cancer. Yet, are ideally placed to effect positive change and minimise distress by recognising the need to redefine the social care worker job description and provide the necessary training and support when a tenant becomes ill. Therefore, the expectations of service organisations concerning the new dimensions of the social care worker role need to change in view of the changing demography, and these changes need to be conveyed to staff alongside the provision of appropriate support and training.

7.4. Summary

Within this chapter, a theoretical framework grounded in this study's data has been developed and proposed. The concept and characteristics of resilience have been critically discussed and its historical and more contemporary use in research has been examined. Participants in this study gained invaluable experience of the challenges supporting a tenant with cancer brings to their existing social care role. As a result, and through their experiences, they have been able to build resilience. If service organisations are able to

acknowledge this cycle of building resilience and put in place adequate training and supports, prior and post resilience can be achieved for social care workers supporting their tenants with cancer.

Finally, it is accepted that inevitably there will always be some individuals who are unable to access prior training and support. However, as a result of the findings of this study, having gained sufficient awareness and identified areas where staff are vulnerable to experiencing a cycle of building resilience, appropriate support can now be put in place to help social care staff build resilience whilst they support their tenants with cancer.

CHAPTER 8

Conclusion

This final chapter reflects on the overall study. Initially it will assess the quality of this study and identify its methodological limitations and strengths. Conclusions will then be drawn and recommendations for practice, policy and research will follow. Finally, a discussion surrounding the dissemination of this study's findings will be presented.

8.1. Review of the study

This thesis reports on a study that was conducted to explore the experiences of paid social care workers supporting people with learning disabilities living with cancer in residential services across Wales. Using Charmaz's (2010) version of constructivist grounded theory, fourteen semi-structured interviews were conducted across two service organisations in Wales. Data were collected and transcribed before being qualitatively analysed using NVivo software. By continuing to use Charmaz's (2010) version of constructivist grounded theory, the cycle through which staff build resilience was developed. This theoretical framework captures the four theoretical

categories of '*role identity*'; '*role ambiguity*'; '*role emotions*'; and '*role resolution*', and the core category '*building resilience*'.

The findings of this study offer some new insights into the experiences of paid social care workers supporting tenants living with cancer in residential services across Wales. When a tenant becomes ill with cancer, staff are involuntarily and largely unknowingly propelled into a cycle of building resilience. By moving through the stages of this cycle, staff were able to build resilience. The theoretical category of '*role identity*' explores accounts of how staff viewed their role. Changes to their current role identity as a result of supporting a tenant with cancer informed the theoretical category of '*role ambiguity*'. The resulting positive and negative emotions to their experiences of role ambiguity were explored in '*role emotions*'. The final theoretical category of '*role resolution*', explored how staff attempted to cope, resolve and prepare for these changes. Through this cycle, staff were able to build resilience.

8.2. Methodological limitations

As I lacked research experience, during the initial interviews I may have limited the extent to which I was able to gather some data, although my interviewing technique improved as the interviews progressed.

Whilst I considered building rapport with participants was vital in gaining rich data, I considered that in the earlier interviews my need to speak more, rather than listen, may have interfered with the participants' responses and sometimes limited their discussion. Having recognised this, I was able to change my approach in subsequent interviews.

The current economic climate and increasing financial constraints within service organisations impacted on recruitment for this study. Two of the nine organisations originally invited to participate in this study declined on the basis of low staffing levels and organisational restructuring. This limited the participation of service organisations, which may have compromised the generalisability of this study's findings. Whilst financial constraints constitute a valid point, it must also be recognised that generalisability is not the primary aim of qualitative research.

8.3. Methodological strengths

Constructivist grounded theory has a variety of strengths. One of the methodological strengths of this study is the flexibility of the methodology used to conduct it. By not having a strict set of rules to adhere to but a set of flexible guidelines, I was able to adopt a pragmatic approach to aspects of the research process such as data collection and theoretical sampling. This flexibility allowed me to collect rich data in a way most suitable to the service

organisations and staff involved in this study. By having the flexibility to interview more than one participant during a twenty-four hour period, I was able to gain a clear and concise picture of the key points arising in the interviews immediately, and direct interview questions accordingly.

As I had no experience of working in this area, I had only a very limited awareness of the kinds of issues and experiences staff might encounter. This awareness was gained as a result of conducting a preliminary literature review at the beginning of this study. This provided me with a relatively objective perspective towards the relationship between employee (research participant) and employer (service organisation). It also facilitated a '*fresh*' glance into the processes of a well-established environment, allowing me to examine the '*expected*' and the '*ordinary*.'

In addition, constructivist grounded theory acknowledges data and analysis as a shared creation of experiences between research participant and researcher. It recognises the resulting grounded theory is both an interpretation of research participants' experiences and those of the researcher. This process is further enhanced by the use of reflexivity, which is also encouraged in constructivist grounded theory.

The use of reflexivity within this project has allowed me to scrutinise my research process and experiences. This has provided me with the opportunity to explore my own attitudes and values and demonstrate how

they may have impacted on this study. For example, as a result of reflexivity I became more aware of my interview technique and how to improve upon it (see page 124 for further discussion). It has also allowed the reader to assess to what extent, and how, my assumptions, interests and prior knowledge have influenced my inquiry. These processes may also have helped to strengthen this study's rigour.

As I was new to this research area prior to commencing this study, I was as nervous as some of the participants prior to interview. This helped to minimise the power differential between the research participant and myself. Additionally, as the foundations of constructivist grounded theory lie in relativism and its appreciation of the multiple truths and realities of subjectivism, I was able to go beyond the surface of phenomena, questioning tacit meanings, values, beliefs and the ideologies of the social care workers.

Recruiting several participants who were supporting/or had supported the same tenant allowed me to explore participants' tacit meanings, their values and beliefs, providing interesting interpretations of their shared events surrounding the tenant. This also provided a picture of how the team functioned together and gave valuable insight into the team's relationships. This helped to clarify participants' experiences and sometimes provided a more accurate picture of the sequence of events during the tenant's illness.

As the majority of participants were still grieving, the timing of this study allowed them to discuss their feelings and talk openly about the loss of their tenant. For many, this provided a cathartic process and provided a particularly rich and in-depth depiction of participants' experiences.

As I am female and the majority (n=13) of participants were female, and of a similar age to me, these similar demographic characteristics may have inadvertently encouraged a '*kindred*' environment where participants may have felt more relaxed and willing to share their feelings (Oakley 1981). As I had my own personal experiences of cancer, which I was able and prepared to share at appropriate times with participants, a process of reciprocity may also have helped to build rapport with the participant (Seidman 2006, Harrison et al 2001).

This study has been conducted in an academically rigorous manner. To ensure academic rigour was achieved throughout this study, I developed an original framework of evaluation criteria based around the transparency and auditability of the research process and product, and the originality and usefulness of the research product. (See chapter 2, page 142 for further details). The originality of this framework is founded on its combination of Strauss and Corbin's (1990) and Charmaz's (2010) work and the way they have been combined in new and untested ways.

*Table 10 Original framework of evaluation criteria for use
with constructivist grounded theory studies*

CRITERIA	QUESTIONS
Research Product	-Are the research findings empirically grounded?
Research Process	-Were the constructs used to generate the grounded theory adequate?
Originality	-Are your categories fresh? -Do you offer new insights? -What is the social and theoretical significance of your work? -How does it challenge current ideas and concepts?
Usefulness	-How can your analysis be applied in everyday settings? -Does it suggest any generic processes? -Can the analysis spark further research? -How does it contribute to knowledge?

Table 10 above provides an overview of this study's original framework of evaluation criteria and outlines the questions that should be asked of the study in a quest to evaluate whether the study has been conducted in an academically rigorous manner. Each criterion in turn will now be discussed and evaluated to demonstrate how academic rigour has been achieved within this study.

8.3.1. Research product and process

Strauss and Corbin (1990) provide a detailed account of the procedures, canons and evaluative criteria specific to their model of grounded theory in an aim to enable critics to accurately judge how the researcher carried out the procedural operations and analysis within the research process and research product. They do not provide a prescription or guidelines on how a researcher should provide this information. Therefore, as their formalised framework for evaluating both the research product and research process is based on transparency and auditability of the research process and research product, the researcher provides the auditing tools in appendix 8, to allow the reader to evaluate the research product and research process of this study for themselves. The criteria for evaluating this study's originality and usefulness will now be addressed in the following sections.

8.3.2. Originality

An explanation of this study's originality will now follow in connection with the specific objectives of this study, which were:-

- To explore the experiences of paid social care staff, such as their understanding, involvement, participation, practice and exposure to people with learning disabilities living with cancer.

- To explore the challenges arising from supporting people with learning disabilities living with cancer, such as the issues that confront staff with difficulty and/or success.
- To explore the support needs of staff working with tenants living with cancer.

Within this study an original contribution to knowledge is made in two areas. Firstly a gap was identified in the current knowledge surrounding the support of people with learning disabilities and cancer. This study was developed to address this gap by providing valuable insight into the experiences of paid social care workers supporting people with learning disabilities living with cancer in residential services across Wales. It has identified that currently paid social care workers supporting tenants with cancer are being expected to undertake healthcare tasks for which they are not receiving training and which are not outlined in their job descriptions. This issue has not been highlighted in previous research. From this, a theory has been proposed suggesting staff build resilience through a cyclical process, namely the cycle of building resilience. The significance of this theory is that it can be used to build resilience in a proactive way.

Secondly since existing evaluation criteria did not adequately address the study design, the researcher has developed an original framework of evaluation criteria for this study (see chapter 2, page 138 and chapter 8, page 345 for further discussion). This framework allows the reader to explore

how the researcher carried out the procedural operations and analysis within the research process and product and judge for themselves whether academic rigour has been achieved within this study.

8.3.3. Usefulness

The criterion for usefulness is explored in terms of how this study's categories offered ways in which people can use its findings in their everyday lives and the implications it may have for current practice and policy work. These can be identified through the key recommendations (see page 350) and dissemination (see page 353) of this study.

Additionally, in consideration of existing policy it may also contribute to the understanding of improving joint working practices across services, which is already recognised within '*Working Together for Wales: A Strategic Framework for the Public Service Workforce within Wales*' (Welsh Government 2012a). It will also increase understanding surrounding the contribution of the social care workforce to health, currently noted in '*Together for health: A Five Year Vision for the NHS in Wales*' (Welsh Government 2012b). Furthermore, whilst this study does not specifically focus on older people with learning disabilities, due to the correlation between ageing and cancer, service organisations may be expected to support increasing numbers of their tenants with cancer as they age.

Therefore, it does have implications on the framework for delivering integrated health and social care for older people as outlined in the draft '*Social Services and Well-being (Wales) Bill*' and on the framework for developing community services, which was issued by the Welsh Government in June 2013, '*Delivering Local Health Care*'.

8.4. Conclusions

The cycle of building resilience presented in this thesis offers some valuable insights into the experiences of paid social care workers supporting a tenant with learning disabilities and cancer living in residential services across Wales. Supporting a tenant with cancer requires significant adjustments to the social care role. These adjustments blur social care role boundaries and produce role ambiguity. Role ambiguity creates a series of role emotions potentially leading staff into a process of role resolution where they attempt to resolve role ambiguity and create positive role emotions, which in turn strengthens their role identity. This cyclical process inadvertently helps staff to build resilience. By understanding this cyclical process, a more proactive approach to building resilience prior to supporting tenants with cancer is now possible.

8.5. Key Recommendations of this study

1. Service organisations should revisit the job descriptions of their social care staff in view of the health needs of their tenants and ensure these job descriptions accurately reflect the mix of skills and duties required by social care staff.
2. Service organisations should provide staff with healthcare training appropriate to the needs of their tenants. Some of this will be in response to long-standing health issues, although where additional needs arise (such as cancer), extra focused training should be provided. Healthcare training should incorporate training surrounding health advocacy, health promotion and surveillance, meeting the health information needs of tenants and mandatory training surrounding awareness and understanding of the Mental Capacity Act (2005) (to be regularly updated).
3. Greater effort should be made across all service providers within all sectors to raise awareness concerning the vital role social care workers play in meeting the healthcare support needs of people with learning disabilities.
4. When a tenant is diagnosed with cancer, service organisations should ensure that a cancer specialist from a cancer organisation such as Macmillan or Tenovus is invited to speak with support staff and answer any questions they may have concerning cancer.

5. Service organisations should ensure there are adequate staffing levels from the outset of a tenant's illness, with levels being reviewed and maintained at all times.
6. Service organisations should make available a combination of clinical supervision, support and counselling for social care workers supporting tenants with cancer.
7. Staff teams supporting tenants with cancer should have the opportunity to debrief both individually and collectively after providing this intense period of support to tenants.
8. Service organisations should support social care workers who organise their tenants' funerals and facilitate the opportunity for tenants to become more involved in planning their own funerals.
9. After a tenant has died and the funeral has taken place, decisions surrounding when the next tenant should move in, should be addressed by service organisations on an individual housing project basis and discussed with the staff team and other tenants.
10. Further research should be considered surrounding the current gaps in empirical evidence outlined throughout this study. These include the need for further research exploring the incidence and prevalence of cancer within the learning disability population, the bereavement needs of both people with learning disabilities and social care workers and the education and training needs of social care workers supporting a terminally ill tenant. Additionally, the gendered dimensions of care, healthcare staff perceptions of the

social care worker role and their understanding of the relationship social care workers share with their tenants should also be explored. So too should the cancer information needs of social care workers, the relationship between relatives and social care staff who are jointly involved in supporting a tenant with cancer, and service organisations' attitudes towards the emotional dimension of the social care worker/tenant relationship.

To conclude, through the knowledge developed in this study, there is an opportunity for social care workers to proactively build resilience prior to supporting a tenant with cancer. This can be achieved by adjusting the social care role identity to incorporate healthcare support. Through training and support, social care roles could become redefined, affording a higher occupational status. This in turn may also encourage greater gender equality within the social care workforce. Finally, amidst current UK policy reviews exploring the nature and future funding of social care and in light of the ageing population and increasing requirement for a larger social care workforce, these proposals may have come at just the right time.

8.6. Dissemination of study findings

A summary of the proposed dissemination of this study's findings is outlined in the knowledge transfer strategy (see appendix 7). This aims to bridge the gap between what is known to improve the experiences of paid social care workers supporting people with learning disabilities living with cancer in residential services and what is actually done to improve support workers experiences. Transferring research findings in practice settings requires a combination of four key goals; a clear strategy, (see appendix 7) a knowledge broker (the researcher), a receptive target audience and funding streams (collaboration from the target audience).

The findings from this research study have already contributed to other substantive areas in this field of research. In November 2012, the Unit for Development in Intellectual Disabilities based at the University of South Wales made an application for funding to the National Institute for Social Care and Health Research for an eighteen month study entitled, *'Residential support workers meeting the health needs of older people with learning disabilities: an exploration of their developmental and support needs'*. This study successfully received £132,520 on 31st July 2013 and has recently commenced.

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Appendices 1 - 8

Appendix 1

A timeline of the history of learning disabilities

DATE	HISTORICAL OVERVIEW
1400	Lunatics admitted to hospitals; treatment consisted of chaining and whipping
1500	<p>Borde (1542) recommends that the insane should 'be kept in a closed chamber and should have a keeper whom he fears.'</p> <p>Witchcraft linked to madness (which included learning disabilities at that time).</p>
1700	<p>Earlier laws against witchcraft are abolished.</p> <p>Regulation of Madhouses Act 1774</p> <p>1794 Malthus noted imbalance between rate of population growth and rate of increase of food supply. Feeble-mindedness considered to be transmitted through the generations. The feeble-minded considered to be a group reproducing at a greater rate than the general population. Rogues, Vagabonds, and other Idle and Disorderly Persons Act (1744) make a distinction between lunatics and vagrants/ paupers.</p> <p>Treatment includes bleeding and emetics.</p>
1800	<p>1828: Lunatic Asylum Regulation Act.</p> <p>Poor Law Amendment Act (1834) separated people considered unable to contribute to the economy into workhouses.</p> <p>The Idiots Act 1886 was the first time the needs of the mentally handicapped were specifically addressed by legislation. In addition to workhouses, people with learning disabilities were often admitted to lunatic asylums, and prisons. The Act introduced registration,</p>

	<p>inspection and admission to specialised asylums. The Lunacy Act (1890), however, did not discriminate between the 'mentally ill and the mentally retarded.'</p> <p>Most care provided by family, social networks and religious organisations.</p> <p>Development of Darwinian theory and belief in natural selection and the deterioration of intelligence.</p> <p>Eugenics, the 'science of improving inborn human qualities through selective breeding' first coined by Francis Galton in 1883. Negative eugenics (inhibiting procreation amongst classes considered socially deviant) brought about by institutionalising.</p>
1900-1946	<p>1909 Royal Commission set up to investigate the 'problem' of the 'feeble minded.'</p> <p>1913: Mental Deficiency Bill. People with learning disabilities now identified as distinct from the mentally ill.</p> <p>The Mental Deficiency Act 1913 legalised the detention of individuals with varying degrees of mental defect. The Act established four classes of mental deficiency: idiot - unable to guard themselves against common physical dangers such as fire, water or traffic; imbecile - could guard against physical dangers but were incapable of managing themselves or their affairs; feeble-minded - needed care or control for protection of self or others; and moral defectives - displaying mental weakness coupled with strong vicious or criminal propensities, and on whom punishment had little or no deterrent effect.</p> <p>The First World War (1914-1918) delayed the implementation of this but the findings of the Wood committee reporting in 1929</p>

	<p>resulted in the acceleration of policy recommending that 100,000 individuals suffering from mental deficiency be immediately institutionalised. The Wood report also noted the reliance institutions had on the labour of inmates for maintenance.</p> <p>The Mental Deficiency Act 1927 gave Local Authorities statutory responsibility for providing occupation and training. Mental deficiency was 'a condition of arrested or incomplete development of mind existing before the age of 18 years whether arising from inherent causes or induced by disease or injury.' 1930s: compulsory sterilisation considered in the UK for people with learning disabilities.</p> <p>Mid 1930s-mid 1940s: Nazi Germany exterminates 'undesirables,' such as those with learning disabilities.</p>
1946-2000	<p>1946 National Health Service Act. Treatment becomes free at point of access.</p> <p>1959: Mental Health Act. Further distinctions between mental illness and a new term, 'mental sub-normality.'</p> <p>Goffman's (1959) book 'Asylums' discussed the disastrous effects of institutionalisation on inmates of asylums.</p> <p>European Convention on Human Rights (1950), Mental Health Act 1957, Howe report (1969) and recommendations of the 1971 White Paper 'Better Services for the Mentally Handicapped' advocating a 50% reduction of hospital places by 1991, reflect different attitudes and contribute to new thinking on learning disability.</p> <p>Wolfensberger's Principle of Normalisation (1972) was highly influential at this time as was the United Nations Declaration of the</p>

	<p>Rights of Mentally Retarded Persons 1971.</p> <p>1980s/90s: many people discharged from old long-stay hospitals in response to White Paper of 1971, also known as the 'deinstitutionalisation movement).</p> <p>2000 – Present. Many more people now living in community and supported settings.</p>
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Source: Atherton 2005

Appendix 2

Interview Guide 1 for Study Participants

Study title: *‘An exploration of the experiences of paid social care staff who have supported and/or currently support people with learning disabilities living with cancer in residential services across Wales: a grounded theory study.’*

Note: As this study is employing a grounded theory approach, it may be necessary to develop and alter these questions as the study progresses, although the number of questions asked of any one participant in any one interview will not exceed ten.

Initial open-ended questions:-

- How and when did you first become aware that the resident you support(ed) has/had cancer?

Intermediate Questions:

- Tell me about your thoughts and feelings when you learned about the diagnosis?
- What emotional impact, if any, does/did supporting this resident with cancer have on you?
- Tell me about the stressors in your situation?
- What coping techniques do/did you use to handle these stressors?

- Who/What is/has been most helpful to you during this period?
- As you look back on this period, are there any other events that stand out in your mind?
- Could you describe the most important lessons you learned through experiencing this situation?

Ending Questions:

- After having these experiences, what advice would you give to someone who may be facing the same circumstances?
- Is there anything else you think I should know to understand this situation better?

(Optional: Is there anything you would like to ask me?)

Interview Guide 2 for Study Participants

- Looking back did your role change and if so how?
- Were you prepared for any changes in your role?
- Do you think you had sufficient experience and knowledge to meet your resident's needs in this regard?
- Did you have a chance to opt out of supporting your resident?
- If you had questions relating to your new role, were your information needs met?
- Were you given the training you needed, i.e. syringe driver, bathing in bed, washing hair in bed?
- If not, how did this make you feel?
- Do you feel that you were able to provide your resident with the care and support they needed?
- If no, what do you think you could have done to improve matters?
- If and when family visited, how did you feel?
- Did you feel that professional healthcare staff welcomed your support and used your knowledge?
- If the team were an important part of your coping strategy, what did the team do or make you feel that particularly helped?
- OR Why do you think the team were important to you during this period?
- Given the same set of circumstances would you support a resident again with cancer?
- If so, is there anything you would do differently?

- Did you support your tenant for a long or short period?
- If it was short, do you think you would have coped if it were for a longer period?

Appendix 3

Participant Information Sheet

Study title: *'An exploration of the experiences of paid social care staff who have supported and/or currently support people with learning disabilities living with cancer in residential services across Wales: a grounded theory study.'*

You are being invited to take part in a study exploring the experiences of paid social care staff that have supported and/or currently support people with learning disabilities living with cancer, in residential services across Wales. Before you decide whether or not to participate, it is important for you to understand why the study is being undertaken and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish.

What is the aim of the research?

Very little is currently known about the support needs and experiences of paid social care staff, supporting people with learning disabilities living with cancer, in residential services across Wales. The study will help us find out more about these issues. The information will be used to inform future policy, educational and practice development in this area.

Who is undertaking the study?

The study is being undertaken by researchers at the Unit for the Development of Intellectual Disabilities (UDID), which is based at the University of Glamorgan, (www.glam.ac.uk/udid) within the Faculty of Health, Sports and Science. The study is part of a postgraduate degree being undertaken by Tina Crimes and a thesis will be written discussing the findings. This study is funded by the University of Glamorgan (www.glam.ac.uk).

What will I have to do?

You will be asked to keep this information sheet, and the contact sheet and then to read and sign a consent form. The researcher will then undertake a face-to-face interview with you, which will be digitally recorded to enable the researcher to record your responses accurately after the interview. You will be asked no more than ten questions about your experiences and the meeting will last around 60 minutes. You may be asked to participate in more than one of these interviews over an eighteen-month period, starting from October 2011 to December 2012 inclusive.

Do I have to take part in the research?

You **do not** have to take part in the study if you do not want to. You can change your mind about participating in the interview(s) at any stage, including during the meeting. You do not have to answer any questions you do not want to answer. You do not have to give your reasons to the

researcher. If you decide not to take part or withdraw from the study at any time you will not be penalised in any way. Should you decide to withdraw from the study you can request that all the information and data collected from you, be destroyed and removed from all study files.

Will anyone else be in the meeting?

There will be no one else in the meeting apart from the researcher, Tina Crimes. If you would like a friend or colleague to accompany you, please let the researcher know so that they can accommodate your request.

What are the possible disadvantages and risks of taking part?

The interview will ask you about your experiences of supporting someone with learning disabilities, living in services where you are employed, who has had or who has cancer during the past five years. For many reasons you may feel uncomfortable, distressed or anxious talking about your experiences. If this is the case, you are entitled to refuse to answer any question you feel uncomfortable with, or to end your participation in the study without having to give a reason. You are **encouraged** to contact any/all of the organisations provided on the contact sheet provided should you require support and/or assistance in dealing with your anxiety or distress at any time.

What are the possible benefits of taking part?

There is no intended direct benefit to you as a participant and we cannot promise that the study will help you in any way. However, the information you provide should you decide to participate will be valuable and the information gained from the study will help us to better understand the experiences and support needs of paid social carers supporting people with learning disabilities, living with cancer in residential services. The information you provide may also help to develop policy, education and practice in this area.

What if there is a problem?

If you have a concern about any aspect of this study, you should speak to the researcher or her supervisors (in confidence), who will do their best to answer your questions:-

Tina Crimes – Researcher (07788765543)

Professor Ruth Northway – First supervisor (01443-483177)

Dr. Robert Jenkins – Second supervisor (01443-483055)

Dr. Penny Llewellyn – Third supervisor (01443-483177)

If you remain unhappy and wish to complain formally, you can do this by contacting the University of Glamorgan Quality Unit at: The Quality Unit, Academic Registry, University of Glamorgan, 1 Llantwit Road, Treforest, CF37 1DL. (01443-480380).

Will anyone know that I have participated in the research?

Everything you say during the interview is **confidential**. Your confidentiality will be safeguarded during and after the study. However, it should be recognised that the researcher is obliged to consult and/or inform any necessary body of any disclosure of information identifying any member of the public at risk of physical or psychological harm. The information you provide will not be fed back to your Managers or any other employee within your organisation. The information you provide will be **anonymised** so that it will not be possible for anyone reading the final report to know that you have taken part in the study. This will be achieved by allocating each research participant with a unique research code, known only to the research team. A master list identifying participants to the research codes data will be held on a password protected computer accessed only by the research team. The digitally recorded interviews will be stored in a locked cabinet, within a locked office, accessed only by the researcher. All electronic data, such as the recorded interview data, will be stored on a password-protected computer known only by the researcher.

What will happen to the results of the research study?

Any data you provide will be securely stored. For example, it will be locked in filing cabinets or on a password protected computer to which only the researcher has access. Should the research be published, information will be presented in a way that will preserve your anonymity. The data that you provide for the study will be analysed and eventually input into a computer programme that will compare other responses with yours. Whilst direct

quotations may be used in any reports and/or publications, no individuals will be identifiable from the data presented. No personal data will be published in this study or any future study. Subject to further ethics approval, the data may be used in the future for further analysis or other research studies. No personal data will be published should the results of the study be re-used. Data collected during this study will be retained securely for a minimum of five years after which it will be disposed of securely in line with the University of Glamorgan's policy and procedures and the Data Protection Act (1998).

Will I receive any feedback on the findings of the research?

We are committed to providing feedback on the findings of the study to everyone who participates in the study. If you provide us with your contact details we will send you a copy of a summary of the findings of the study. Alternatively you can contact us at tcrimes@glam.ac.uk or telephone us on any of the numbers overleaf, and we will send it to you. The summary of the findings of this study will not be available before January 2014.

Who has reviewed this study?

The University of Glamorgan's, Health, Sport and Science Faculty Ethics Committee has reviewed and approved this study.

Can I find out more about this study and ask some more questions?

Please feel free to contact Tina Crimes via email tcrimes@glam.ac.uk or ring her on (mobile number) 07788765543, if you would like some more information on this study or if you have any further queries, concerns or questions relating to this study.

Thank you for taking the time to read this information sheet and for considering your participation in this study.

Informed Consent Form for Study Participants

Study title: *‘An exploration of the experiences of paid social care staff who have supported and/or currently support people with learning disabilities living with cancer in residential services across Wales: a grounded theory study.’*

I agree to take part in the above Faculty of Health, Sport and Science (University of Glamorgan) research study. I have had the study explained to me, and I have read the Participant Information Sheet. I understand that agreeing to take part means that I am willing to: -

- Answer questions in a face to face interview with the researcher
- Allow the interview(s) to be digitally recorded.
- Make myself available for a further interview should that be required.
- Allow anonymous and unidentifiable direct quotations to be used in any report and/or publication.
- Allow for data already collected as a result of my participation in the study still to be used in the study, should I decide to withdraw from the study, unless I state otherwise verbally and in writing to the researcher.

Data Protection

This information will be held and processed for the following purposes: -

- To identify the experiences and support needs of paid social care staff supporting people with learning disabilities living with cancer in Wales.
- To inform policy, education and practice development in this area.
- For possible future further research and/or publication.
- For the completion of a postgraduate research degree by Tina Crimes.

I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on this or any future study, or to any other party. No identifiable personal data will be published. The identifiable data will not be shared with any other organisation. Any information I provide **will not** be fed back to my Managers or any other employee of the organisation where I am employed.

I understand that the researcher is obliged to consult and/or inform any necessary body of any disclosure of information identifying any member of the public at risk of physical or psychological harm.

I agree to the University of Glamorgan recording and processing this information about me. I understand that this information will be used only for the purposes set out in this statement and my consent is conditional on the University complying with its duties and obligations under the Data Protection Act 1998.

Withdrawal from the study

- I understand that my participation is voluntary, that I can choose not to participate in part or all of the study, and that I can withdraw at any stage of the study without being penalised or disadvantaged in any way. I also understand that all data already collected as a result of my participation in the study will still be used in the study, should I decide to withdraw from the study, unless I state otherwise verbally and in writing to the researcher.

Further publication of analyses

I give consent for my contributed data to be used in ethically approved further analyses, future publications or future research studies undertaken by Tina Crimes, Professor Ruth Northway, Dr. Robert Jenkins and Dr. Penny Llewellyn as long as the data remains anonymous.

Please tick to confirm

I confirm I have read and understood the Participant Information Sheet and the Participant Consent Form for the above study.

I confirm I have been given information about the above study and had time to consider it, ask questions, and had those questions answered satisfactorily.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without detriment to me.

By signing below I am indicating that I agree to participate in the study, 'An exploration of the experiences of paid social care staff who have supported and/or currently support people with learning disabilities living with cancer in residential services across Wales: a grounded theory study.'

Participant

Name: (Please print)

Signature: Date:

Independent witness to participant's voluntary and informed consent:

I believe that understands the above study and gives her/his consent voluntarily.

Name: (Please print)

Signature: Date:

Address:

Contact Sheet for Study Participants

Study title: *'An exploration of the experiences of paid social care staff who have supported and/or currently support people with learning disabilities living with cancer in residential services across Wales: a grounded theory study.'*

You are being invited to take part in a study exploring the experiences of paid social care staff, supporting people with learning disabilities living with cancer in Wales. You may have agreed to participate in a face-to-face interview with a researcher.

The interviewer will ask you about your experiences of supporting someone with learning disabilities living in services where you are employed, who has had or who has cancer. For many reasons you may feel uncomfortable, distressed or anxious talking about your experiences. If this is the case, you are entitled to refuse to answer any question you feel uncomfortable with, or to end your participation in the study without having to give a reason and without being penalised.

The researcher is not qualified to provide professional support or counselling services and therefore, if you experience any distress and/or anxiety and wish to seek professional help in the first instance you may wish to contact your own personal General Practitioner either through surgery opening

hours, or the out of hours service. If you would prefer not to contact your General Practitioner, or having contacted your General Practitioner require further support, please contact any of the organisations listed below: -

Cancer Information and Support Services

(South and South West Wales)

01792-655025 / 01639-642333 / 01267-679149

www.cancerinformation.org.uk. Service for cancer patients, carers, families and friends. Information, counselling drop-in, complementary therapies, library.

Macmillan Cancer Support Line

(Free phone 0808-8080000 - Monday to Friday 9am to 8pm)

www.macmillan.org.uk. Support, care and practical and emotional support for people living with cancer including families, friends, carers.

NHS Direct

(Free phone 0845 4647)

www.nhsdirect.nhs.uk. For health advice and reassurance, 24 hours a day, 365 days a year.

Palliative Care for People with Learning Disabilities

Dr Irene Tuffrey-Wijne (Chair), PCPLD Network, St George's University of London, Division of PHSE, Cranmer Terrace, London SW17 0RE. Tel 07977 260967 / www.pcpld.org/ The PCPLD Network is a voluntary organisation. In 1998, a small group of learning disability and palliative care professionals

came together, concerned by their experience that people with learning disabilities who were facing a life-limiting illness did not seem to access the same services or receive the same quality of service as the rest of the population.

Samaritans

(Free phone on 08457-909090, 24 hours a day, 365 days a year)

www.samaritans.org.uk. Samaritans volunteers listen in confidence to anyone in any type of emotional distress, without judging or telling people what to do. Samaritans doesn't offer advice, but by encouraging people who contact them to talk about their feelings they are able to help them explore all the options they have.

Tenovus Cancer Support Line

(Free phone 0808 – 8081010 – Monday to Friday 9am to 5pm)

www.tenovus.com. Telephone information, support and counselling for cancer patients, friends, families and carers.

Appendix 4 – Ethical approval

University of Glamorgan

Prifysgol Morgannwg

Faculty of Health, Sport and Science
Cyfadran Iechyd, Chwaraeon a Gwyddoniaeth



21 June 2011

Tina Crimes,
C/O Faculty of Health Sport and Science
University of Glamorgan

Dear Ms Crimes,

Re: 'An exploration of the experiences of paid social care staff who have supported and/or currently support people with learning disabilities living with cancer in Wales: a grounded theory study.'

I am writing to confirm that on 21 June 2011, the Faculty of Health, Sport, and Science Ethics Sub Group approved your revised submission for ethical approval.

If you have any queries about the group's decision, please do not hesitate to contact me.

Yours sincerely,

Prof. Paul Rogers
Faculty Ethics Champion



INVESTORS IN PEOPLE | BUDDSODDWR
IN PEOPLE | MEWN POBL



Professor/ Yr Athro Donna M Mead O.B.E.
Dean of Faculty/Deon y Cyfadran
University of Glamorgan/Prifysgol Morgannwg, Pontypridd, CF37 1DL, UK/DU
Tel/Ffôn 01443 483094 Fax/Ffacs 01443 483118
www.glam.ac.uk

Julie E Lydon Vice-Chancellor/Is-Ganghellor

Appendix 5

Letter 1 to Chief Executive Officers of service organisations inviting participation

3rd October 2011

Dear Sir/Madam,

Re: 'An exploration of the experiences of paid social care staff who have supported and/or currently support people with learning disabilities living with cancer in residential services across Wales: a grounded theory study.'

I am a full-time mature student at the University of Glamorgan and am currently studying for a PhD. I am being supervised by Professor Ruth Northway, Dr. Robert Jenkins and Dr. Penny Llewellyn based at the Unit for Development in Intellectual Disabilities.

Very little is currently known about the support needs and experiences of paid social care staff supporting people with learning disabilities with cancer. As part of my PhD, I am carrying out the above study, which will help us find out more about these issues.

This is an important area for study and presents an opportunity to be involved in research which will hopefully be of great interest to not only

services and agencies in Wales, but also more widely. Therefore, I should welcome the opportunity to meet with you, or with a colleague to discuss this study in more detail and to discuss the potential participation of your agency. I have enclosed a brief summary of the study although full details can be supplied if necessary. However, in brief, participating agencies will be required to:

1. Identify relevant staff and obtain consent for their details to be passed to the researcher.
2. Provide a list of staff and their contact details to the researcher by email.
3. Permit staff to be involved in a face-to-face interview for one hour on possibly more than one occasion.

I would like to follow this letter up in a few weeks by telephone to discuss your initial reaction to this request. However, in the meantime, please feel free to contact me by telephone (07788765543) or by email (tcrimes@glam.ac.uk) .

Thank you for your interest, and I look forward to hearing from you.

Yours sincerely,

**Letter 2 sent to Chief Executive Officers of service organisations
inviting participation.**

4th January 2012

Dear

Re: 'An exploration of the experiences of paid social care staff who have supported and/or currently support people with learning disabilities living with cancer in residential services across Wales: a grounded theory study.'

Further to my previous letter to you in October 2011 introducing myself and the above study I am writing to advise you of an adjustment that has recently been made to this study. Initially, the timeframe for paid social carers to have supported a person with learning disabilities living with cancer was set at two years, however as the study has progressed, it has become apparent that there are members of staff who have vivid memories of supporting a service user within a larger timeframe of five years. Therefore, the study has been adjusted to incorporate this extended timeframe and is now requesting participation from any paid social care staff that currently support or have supported a person with learning disabilities living with cancer in residential services in the past **five years**.

Therefore, as previously requested, I would be extremely grateful if you could return to your residential service staff and: -

1. Identify relevant staff and obtain consent for their details to be passed to the researcher.
2. Provide a list of staff and their contact details to the researcher by email.
3. Permit staff to be involved in a face-to-face interview for one hour on possibly more than one occasion.

With this in mind, I attach amended copies of the participant information sheet, consent form and contact sheet and also a study summary for redistribution to your staff.

I would like to follow this letter up in a few weeks by telephone to discuss your progress. However, in the meantime, please feel free to contact me by telephone (07788765543) or by email (tcrimes@glam.ac.uk) should you wish to discuss the study or the changes further.

Thank you for your continued interest, and I look forward to hearing from you.

Yours sincerely,

Study summary enclosed with both letters to service organisations inviting participation.

STUDY SUMMARY

Study title: 'An exploration of the experiences of paid social care staff who have supported and/or currently support people with learning disabilities living with cancer in residential services across Wales: a grounded theory study.'

Your agency is being invited to take part in a study exploring the experiences of paid social care staff that have supported and/or currently support people with learning disabilities living with cancer, in residential services across Wales.

What is the aim of the research?

Very little is currently known about the support needs and experiences of paid social care staff, supporting people with learning disabilities living with cancer, in residential services across Wales. This study will help us find out more about these issues. The information will be used to inform future policy, educational and practice development in this area.

Who is undertaking the study?

The study is being undertaken by researchers at the Unit for the Development of Intellectual Disabilities (UDID), which is based at the University of Glamorgan, (www.glam.ac.uk/udid) within the Faculty of Health, Sports and Science. The study is part of a postgraduate degree being undertaken by Tina Crimes and a thesis will be written discussing the findings. The study is funded by the University of Glamorgan (www.glam.ac.uk).

What will the agency have to do?

The agency will be asked to contact staff who have supported and/or who currently support residents living with cancer in your agency over the past five years and ask them to consent to their contact details being passed to our researcher, Tina Crimes. If staff members consent for their contact details to be passed to the researcher, the agency will be required to provide the researcher with a list of names, work addresses and contact telephone numbers by email, to enable her to contact staff and invite them to participate in the study.

If staff members agree to participate in the study they will be given an information sheet, and a contact sheet and then asked to read and sign a consent form. (Please find a copy of these forms attached for your information). The researcher will then undertake a face-to-face interview with the staff member at a mutually convenient time and venue, which will be digitally recorded to enable the researcher to record staff responses

accurately after the interview. The staff member will be asked no more than ten questions about their experiences and the meeting will last approximately 60 minutes. Staff may be asked to participate in more than one of these interviews over an eighteen-month period, starting from October 2011 to December 2012 inclusive.

Tina Crimes

Appendix 6

Service organisations job descriptions

Job Description

SUPPORT WORKERS

RESPONSIBLE TO: Team Manager

ACCOUNTABLE TO: Director of Operational Services

ROLE: To support and enable service users with disabilities

According to their individual needs, through maximum participation in service provision. This will involve working as part of a team within a flexible rota to include weekends, bank holidays and sleep-in duties.

1. Responsibilities and Support To Service Users

- 1.1 To provide continuous and consistent support, both physical, practical and emotional which reflect any individual changing needs in line with the service users identified desires. The support should be provided in a manner that promotes independence and in a non-discriminatory manner.

Physical Support required by individuals may include: household and domestic tasks, shopping and diet/food preparation, personal hygiene, dressing and personal appearance.

Practical Support, Service Users should be assisted to undertake all tasks themselves. The level of assistance of support will vary according to individual need. The main aim is for Service Users to be provided every opportunity to participate, with support if necessary, to be responsible for all tasks and activities inside and outside their home.

Emotional Support required by individuals may include: the offer of support in a sensitive manner with the ability to empathise and actively listen. To offer advice and guidance when supporting Service Users to make informed decisions and exercise their rights.

- 1.2 To ensure that Service Users are encouraged and empowered, to express their opinions and views in all areas of decision-making, both at individual and organisational level.
- 1.3 To assist and encourage Service Users to become integrated members of their local community, by actively promoting physical and social presence in community based facilities, e.g. educational, occupational, social and leisure.
- 1.4 To act as appropriate role models, when supporting Service Users to participate in day and evening opportunities. Dressing and acting appropriately to participate in such daily activities.
- 1.5 To liaise with families, staff and relevant services to maintain a high standard of support and provision of a quality service.
- 1.6 To contribute to the development of individual Service Users by assisting with the planning and practical implementation and monitoring of Opportunities and Goals identified in:

- i. Activity and Support Plans

- ii. Opportunity Plans
- iii. Teaching Plans

1.7 To accompany Service Users on holiday by agreement with the Line Manager whilst ensuring compliance with the requirement/ expectations of the post.

2. Staff and Personnel Issues

- 2.1 To participate and contribute to supervision and appraisal sessions, as agreed with Line Manager.
- 2.2 To attend and actively participate in both mandatory and relevant training events. To keep accurate records of training and personal development, i.e. personal portfolio.
- 2.3 To identify one's own training needs in consultation with appropriate Line Manager.
- 2.4 To effectively communicate with the staff team and colleagues, regarding issues relating to individual Service Users, the house and the organisation.
- 2.5 To keep accurate records of hours worked, and the completion and submission of timesheets.
- 2.6 To participate and contribute to relevant team and organisational meetings.

3. Household and Administrative Responsibilities

- 3.1 To assist in maintaining accurate records, i.e. Service User's personal records, house records, communication books, diaries, food and petty cash expenditure.
- 3.2 To comply where necessary with the requirements of the Registered Homes Act.
- 3.3 To be familiar with Health and Safety at Work Regulations, and to ensure effective implementation during a span of duty. To assist and liaise with team members in maintaining acceptable standards for the maintenance and security of the house. To report, and where necessary deal immediately with malfunctioning equipment.
- 3.4 To successfully undertake a medication proficiency test. To keep up to date with knowledge and understanding of Medication Policy.
- 3.5 To administer, supervise and maintain accurate records relating to all medication administered to Service Users in accordance with Sterling's policy and procedure.
- 3.6 To have an understanding of all financial and administration systems in operation in the home to ensure accurate records are maintained.
- 3.7 To monitor and maintain accurate records for the income and expenditure for Service User's personal finances.

4. Organisational Responsibilities

- 4.1 **Confidentiality.** To fully understand and observe all matters concerning Service Users and staff are kept strictly confidential to individual houses, staff teams and Sterling. **Any breach of the above may be subject to disciplinary action.**
- 4.2 To have an understanding and commitment to Sterling's Aims and Objectives, and to be familiar with, and implement any individualised policies and procedures which may affect specific Service Users.
- 4.3 All staff must be prepared to work at any of Sterling's houses, and must recognise and be prepared to meet the changing support needs of service users in accordance with Sterling's policy on the deployment of staff.
- 4.4 To contribute to internal and external monitoring and review systems.
- 4.5 To have an awareness of, and comply with Sterling's Equal Opportunities Policy.
- 4.6 To have awareness, understanding and commitment to Sterling's Operational Policy and Procedures.
- 4.7 To be prepared to accept other duties and responsibilities commensurate with the post in light of changing circumstances.

N.B. This Job Description is subject to an annual review and any reasonable adjustment in accordance with changing and developing needs of the organisation.

Person Specification

Support Worker

There are no essential experience requirements as it is anticipated that candidates will bring to the job a variety of employment and life experiences, which will be of relevance. However, the following abilities are **desirable**:

DESIRABLE

- A commitment to, and a belief of, valuing all people as equal regardless of any perceived disability.
- A commitment to providing an effective role model.
- An ability to support people with learning disabilities in a flexible but safe environment.
- An ability to respond to the emotional needs of people with learning disabilities.
- The ability to support people with learning disabilities to make and maintain contacts in the local area.
- The ability to respond to the changing needs of people with learning disabilities.
- The ability to communicate effectively verbally and in writing.
- Skills in home making.
- The ability to give support in the day-to-day management of the household budget.
- A commitment to confidentiality.
- The ability to work on own initiative.
- The ability to work as a member of a team.
- A commitment to personal development.

- An ability to work flexibly (including shift work) in line with service needs.
- Demonstrate a commitment to work towards a Care qualification.
- Possession of a full car driving licence.

Job Description

Senior Support Worker

Responsible to: Team Manager

Responsible for: *Working closely with and as directed by the Team Manager, To provide and role model high quality person centred care and support to service users.*

1. To work with the Team Manager to plan rota's that meets the needs of people being supported, including any changes in needs or staff availability.
2. Work with service users to develop person centred plans in a manner and format that suits the individual service user.
3. To co-ordinate necessary arrangements with/for service users to ensure their individual needs are met whilst ensuring individuals are fully involved in all aspects of their support whether at home, in their occupation and in their local communities.
4. Provide high quality care and support to service users and tenants in a manner that supports person centred approached
5. Work with families and other professionals to ensure individuals' needs are met acting also as a good representative for Sterling.
6. Work flexibly, using initiative and constantly seeking improvement of support provided

7. Continue to learn and grow in your role in accordance with the needs of the people supported.
8. Communicate effectively with all, verbally and in writing.
9. Carry out administrative tasks as directed by the Team Manager.
10. To delegate effectively to Support Workers to ensure the consistent high quality support within the service.
11. To actively cooperate with the Team Manager over any other reasonable tasks to ensure the successful running of the service.
12. Behave at all times in a manner that is consistent with Sterling's Vision, Mission and Values statements including the Care Council's Code of Conduct for Social Care Staff. Acting at all times in a manner that is consistent with Sterling's Internal Policy and Procedure framework.

Note - *This Job Description is subject to review and to reasonable adjustment in accordance with changing and developing needs of the organisation.*

Person Specification

Senior Support Worker

Applicants must be able to demonstrate the following:

- A minimum of 12 months experience of working with people with a disability in a residential setting.
- The ability to liaise appropriately and professionally with professionals, families and members of the community.
- A commitment to and a belief of valuing all people as equal regardless of any perceived disability.

- A commitment to providing an effective role model.
- An ability to make effective decisions within delegated authority.
- An ability to undertake appointee-ship for tenants where necessary.
- An ability to develop, implement and monitor person centred plans in accordance with each individuals needs.
- An ability to plan.
- The ability to give support in the day-to-day management of the household budget.
- Possession of a full car driving licence.
- The ability to work on own initiative.
- The ability to work as a member of a team.
- An ability to work flexibly (including shift work) in line with service needs.
- Demonstrate a commitment to work towards a care qualification.

Appendix 7

Summary of the Knowledge Transfer Strategy

Main Challenge

The main challenge of knowledge transfer within the health and social care field is bridging the gap between what is known to improve health and social care and what is done to improve health and social care. Transferring research findings in practice settings requires a combination of four key goals:-

1. A clear strategy (attached)
2. A knowledge broker (myself)
3. A receptive target audience (yourselves)
4. Funding streams (collaboration from target audience)

Overall Aim

The overall aim of this knowledge transfer is to reduce the health inequalities experienced by people with learning disabilities, improve the experiences they have when living with cancer, and equipping staff with the appropriate toolkit to provide the support they need.

Target Audience	Key Objective	Timing	Knowledge Transfer Method
Who to engage?	Why to engage?	When to engage?	How to engage?
Private and voluntary learning disability residential services	<p>To feed project findings back to project participants/invitees.</p> <p>To inform current practice.</p> <p>Raise awareness of current issues and the need for further research to be funded in this area.</p> <p>Raise awareness of the need to develop and fund a 'findings to practice' programme** (Please see further information at the end of this table).</p>	Post Viva September/ October 2014	<p>Distribution of Executive Summary.</p> <p>Individual presentations of findings.</p> <p>Website</p> <p>Social media (facebook, twitter, weekly blog)</p> <p>Submit proposal and funding bid for 'findings to practice' programme.</p>
Local Authority Learning Disability Teams across South Wales.	To inform current practice and raise awareness of the current issues faced by people with learning disabilities and social care staff supporting them.	Gather contact details at the end of July 2014. Make contact September/October 2014 (post Viva).	<p>Distribution of Executive Summary.</p> <p>Individual presentations of findings.</p> <p>Website</p> <p>Social media</p>
Welsh Government	The Learning Disability Implementation Advisory Group (LDIAG) should be made aware of any research findings that	Post Viva, September/October 2014.	<p>Press release.</p> <p>Executive Summary.</p> <p>An offer to discuss the research findings in more</p>

	<p>may impact on the lives of people with learning disabilities.</p> <p>They are responsible for advising the Welsh Government of recent developments to enable further dissemination of the research findings to other government departments, such as Welsh health authorities, Public Health Wales, inform the National Cancer Plan, etc.</p> <p>To raise awareness of the issues and the need to develop and fund a 'findings to practice' programme **</p> <p>To highlight the need for further research in this area.</p>		<p>depth and/or a presentation.</p> <p>Website.</p> <p>Social media</p> <p>Submit proposal and funding bid for 'findings to practice' programme.</p>
GP Consortiums (Possibly to extend to palliative care providers such as hospices etc.)	To engage primary health care providers in the area of learning disabilities and raise awareness of the issues that people with learning disabilities living with cancer and social care workers encounter.	Post Viva, September/ October 2014.	<p>Executive Summary.</p> <p>Individual presentations.</p> <p>Website</p> <p>Social media.</p> <p>Develop and offer an 'awareness workshop'*** (Please see further information at the end of this table)</p>
National cancer charities (Macmillan and Wales centric	To raise awareness of the issues and the need to develop and fund a 'findings to practice' programme.	Post Viva, September/ October 2014	<p>Executive Summary</p> <p>Individual Presentations</p> <p>Conferences</p> <p>Website</p>

Tenovus)	To highlight the need for further research in this area.		Social media. Offer an 'awareness workshop' and submit proposal and funding bid for 'findings to practice' programme.
Learning disability charities (Mencap, Learning Disability Wales, PCPLD Network, BILD)	To raise awareness of the issues and the need to develop and fund a 'findings to practice' programme. To highlight the need for further research in this area.	Post Viva, September/October 2014	Executive Summary Individual Presentations Conferences Website Social media. Submit proposal and funding bid for 'findings to practice' programme.
Academic community (to specifically include Tizard, iHAL, CeDar)	To highlight the research results and current issues and need for further research in this area.	Post Viva, September/October 2014.	Publish journal articles Attend conferences and research fayres. Website Social media Publish a book from the PhD thesis.
Paid social carers	Establish and develop direct and continual engagement with paid social carers to provide ongoing support, awareness and encourage discussion between all interested parties, i.e. GPs, academics, cancer and learning disability charities,	Post Viva, September/October 2014.	Executive Summary Presentations. Website Social media

	government departments.		
People with learning disabilities	To ensure the voices of people with learning disabilities are being heard.	Post Viva, September/ October 2014.	Easy read format executive summary and main report. Website Social media
Kings Fund (Charity that seeks to understand how the NHS in England can be improved).	To ensure the Kings Fund are up to date with issues and events affecting the NHS in Wales.	Post Viva, September/ October 2014.	Executive Summary
NISCHR for social care and health research	To raise awareness of the issues and the need to develop and fund a 'findings to practice' programme. To highlight the need for further research in this area.	Post Viva, September/ October 2014.	Executive Summary Presentations. Website Social media
Velindre and Singleton cancer hubs.	Establish and develop direct and continual engagement with the cancer hubs to provide ongoing support, awareness and encourage discussion between all interested parties, i.e. GPs, academics, cancer and learning disability charities, government departments.	Post Viva, September/ October 2014.	Executive Summary Presentations. Website Social media
Maggi centre in Swansea/Wales	Establish and develop direct and continual engagement with Maggi centres to provide	Post Viva, September/ October 2014.	Executive Summary Presentations. Website

	ongoing support, awareness and encourage discussion between all interested parties, i.e. GPs, academics, cancer and learning disability charities, government departments.		Social media
ARC – Association of Residential Care Providers	Establish and develop direct and continual engagement with ARC to raise awareness of needs and issues.	Post Viva, September/October 2014.	Executive Summary Presentations. Website Social media
ESRC	To develop a conceptual impact and raise awareness of research needs.	Post Viva, September/October 2014.	Executive Summary Presentations. Website Social media

***** Findings to Practice Programme***

In recent years there has been plethora of work investigating specific problems related to service provision and experiences of people with learning disabilities living with cancer, such as health screening, communication, late diagnosis, etc. As a result of this, there also seems to be a plethora of ‘best practice’ models, recommendations and guidelines, few of which seem to be followed or implemented in practice. This has led to ‘best practice fatigue’ amongst front line services.

In response to this and the need to improve the experiences of people with learning disabilities living with cancer in services across Wales, this

programme will be developed, managed and co-ordinated by the knowledge broker (the researcher) and would be designed for the sole purposes of responding to, designing, co-ordinating and managing the transfer of the project knowledge from the research findings to practice, both in physical terms, such as training and social cultural terms, such as staff attitudes.

From the research findings, the knowledge broker will establish a current practice audit and staff needs assessment. These will be tested for legitimacy and accuracy by a survey conducted with a sample of staff through social media networks. Once legitimized, a series of workshops, both attitudinal and practice based (to include workshops on advocacy, consent, basic healthcare tasks, early signs, facts about cancer, facts about dementia, health promotion, counselling skills, palliative care) will be designed and delivered across Wales to all paid social care staff across sectors to re-skill staff and equip them with the toolkit they need to provide the support people with learning disabilities living with cancer need.

***** *Awareness Workshop***

From this research it is evident that awareness amongst healthcare service providers is unacceptably low, particularly amongst primary healthcare providers, concerning the issues people with learning disabilities with cancer face. As primary care trusts are now being replaced by GP consortiums it seems an ideal opportunity to raise awareness at a far greater local level.

This workshop would be for existing healthcare staff although it could be widened to catch other relevant staff if necessary (i.e. speech therapists, occupational therapists, audiotherapists, etc.). GPs, nurses, nursing assistants, hospice staff and anyone else interested in participating, will be invited to attend an awareness workshop on the social based issues that face people with learning disabilities with regard to their age-related illness generally and specifically with cancer. Information concerning the paid social carers role and issues surrounding advocacy, consent, next of kin, etc. will also be included in this workshop.

Appendix 8

Auditing tools for use in evaluating this study's research process and research project

EVALUATION TOOL	LOCATION
NVivo software has been used to provide an audit trail of this study. All study documents are contained on the NVivo study file entitled 'Cancer and Learning Disabilities'.	USB memory stick. Documents contained in NVivo study file entitled 'Cancer and Learning Disabilities' (available upon request).
A reflexive journal demonstrates the researcher's scrutiny of her research experience. It allows the reader to assess the researcher's decisions and interpretations and the extent to which the researcher's assumptions, positions and interests influenced inquiry.	As above. File located under 'Internals/Sources'.
Two maps visualising the conceptual analysis of the study.	As above. File located under 'Models'.

<p>A literary style of writing the research findings has been provided, which is evocative of, and faithful to, participants' experiences and provides transparency of participants' experiences.</p>	<p>See chapters four to seven for research findings and discussion.</p>
<p>An external peer debrief took place in October 2012. This peer debrief reviewed the data analysis and offered additional perspectives for data analysis and suggested further avenues to investigate. A peer debrief summary report was provided in November 2012. A meeting followed between the peer debriefer and the researcher in March 2013 to discuss the peer debriefs findings.</p>	<p>USB memory stick. Documents contained in the NVivo study file entitled 'Cancer and Learning Disabilities'. Peer debrief summary report and report with comments are located under 'Internals/Sources/Evaluation Criteria'.</p>
<p>An external inquiry auditor has examined the NVivo audit trail of this study and is satisfied it is navigable and fit for purpose.</p>	<p>USB memory stick. Documents contained in the NVivo study file entitled 'Cancer and Learning Disabilities'. Inquiry auditor report located under 'Internals/Sources/Evaluation Criteria'.</p>

<p>Evaluation criteria monitoring table has been regularly updated indicating the researcher's progress on each criterion.</p>	<p>USB memory stick. Documents contained in the NVivo study file entitled 'Cancer and Learning Disabilities'. Evaluation criteria monitoring table located under 'Internals/Sources/Evaluation Criteria'.</p>
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